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# Families with Severe Medical Conditions in Children: Effects and Interventions

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Families with Severe Medical Conditions in Children:  
Effects and Interventions

by

Morgan Wilson, B.A.

MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
The University of St. Thomas and St. Catherine University  
St. Paul, Minnesota  
In Partial fulfillment of the Requirements for the Degree of

Master of Social Work

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Harriet Kohen, LICSW

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

## Abstract

Parents and primary caregivers are the most important providers of support and care for their children. Families with children with chronic or life-threatening medical conditions face many challenges that the average family does not. The purpose of this research project was to discover what the effects of having a child with a chronic or severe illness are on the family system. This was done by finding out what has been the most helpful to the family and each of its members during the time since the child has been diagnosed and by finding out what has been challenging to the family throughout their experience. The purpose was also to find out how professionals, specifically social workers, can be of more service to these families. This study used a qualitative research design to gather data from 5 caregivers of 5 children with different chronic or life threatening medical conditions, using in depth interviews. Many common themes were found across diagnoses. As compared to the current literature, many similarities and some differences were found pertaining to the parents, to the ill child, and to the child's siblings. As an example, the most common negative impacts or challenges on the parents that were reported in this study were handling the initial diagnosis, seeing the child suffer, having fear of harming the child more, juggling work and treatment, lack of understanding and social support from relatives and friends, a negative impact on marriage, handling insurance and finances, and having to repeat their stories over and over. Other notable findings included negative impacts on other family members, helpful coping strategies for family members, and themes for social workers. These findings, along with others, have many implications for clinical social work within and outside of the medical field.

*Key words: Chronic illness, terminal illness, children, social work, parents*

## SEVERE MEDICAL CONDITIONS IN CHILDREN

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Families with Severe Medical Conditions in Children:  
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The diagnosis of a chronic medical condition, severe illness, or chronic disease can be a shocking and painful experience for a family, especially when it is that of a child. Receiving medical attention, education, and everyday support may be a daunting and isolating experience for families. However, according to Anderson and Davis (2011), the estimated prevalence of pediatric chronic illness indicates that “31% of children under the age of 18 have a chronic illness, bringing the national total to 18 million,” (p. 416) and according to Meltzer and Johnson (2004), “approximately 1 million children have a chronic physical condition that requires ongoing and comprehensive medical care,” (p. 317).

A chronic disease, according to the World Health Organization, is a disease of “long duration and generally slow progression.” The Center for Managing Chronic Disease defines it as “a long-lasting condition that can be controlled but not cured.”

When a child is diagnosed with a chronic disease or a severe medical condition, there may be a flood of emotions for the family and there will be many changes that will need to take place. There may be specific diets, medications, doctor visits, procedures, specialized supervision, or other tasks that will need to be taken into account to accommodate and provide for the child. These needs may put extra pressure on families that not everyone can relate to. It is almost inevitable that these challenges will have a mental, emotional, or physical effect on the child who is ill and the parents and siblings as well. Families will need to adjust to these changes and new routines, and this takes time and support from others.

Hovey (2005) states that “the diagnosis of a long-term illness within a family is disruptive of the family process of orderly change and development” and “when that illness becomes a chronic condition, the impact on the family and each of its members is immense,” (p. 84).

The research has shown that all family members, including parents, siblings, and the chronically ill children themselves, are in need of professional support throughout these times, (Ferrari, 1986; Fisher, 2001; George, Vickers, Wilkes, & Barton, 2006; Hallström & Elander, 2007; Jerrett, 1994; Melnyk, Feinstein, Moldenhouer, & Small, 2001; Menke, 1987). Fisher (2001) found that, for many parents, the diagnosis brought a period of adjustment (to a new way of life) that involved physical and psychological adaptations that many parents could not foresee. Hallström & Elander (2007) found that along with the constant need to optimize the child’s health, that the family needs support to relieve the situation and to cope, and the family needs support to maintain function and stability. In their review of evidence-based practices with families with ill children, Anderson & Davis (2001) found that effective therapeutic practices that developed coping skills within the family were scarce. Mussatto (2006) found that a thorough understanding of the variables that influence adjustment and adaptation to the stress is required to assess risk for poor adaptation among children and families with chronic illness. Children and families are resilient by nature, but successful adaptation requires ongoing understanding and support from others, (Mussatto, 2006).

Social workers have a unique role in the medical field; they may be challenged with serving families who are going through a medical crisis. Anytime a child’s health, or life, is at risk, social workers and practitioners can offer their knowledge and support to



meet the psychological, emotional, and sometimes physical or financial needs of the families. However, in order for social workers, both in the medical field and in other service areas, to offer tangible, helpful services, to implement evidence-based interventions and to implement family specific interventions, there must be research from which they can build their practice.

The purpose of this research project is to discover what the effects are of having a child with a chronic or life-threatening illness on the family system are by (a) finding out what has been the most helpful to the family and each of its members during the time since the child has been diagnosed and by (b) finding out what has hindered or been challenging to the family throughout their experience, and the purpose is to also (c) find out how professionals, specifically social workers, can be of more service to these families. The following research questions will be examined: What are the effects of having a child with a chronic illness? And how can social workers be more effective in treating families of children with chronic or severe illnesses?

## **Literature Review**

### **What is Chronic Illness?**

Chronic illness is an umbrella term used to describe different types of ongoing health conditions. Coffey (2006) defines chronic illness as “an illness that is long term and is either not curable or has residual features that result in limitations in daily living requiring special assistance or adaption,” (p. 51).

A list of some examples of chronic illnesses include asthma, cancer, cardiac disease, cerebral palsy, congenital disabilities, cystic fibrosis, epilepsy, gastrointestinal disorders, hematological disease, juvenile rheumatoid arthritis, inflammatory bowel

disease, nephritic syndrome, rheumatic disease, sickle cell disease, and spina bifida, (Anderson & Davis, 2011). Hordvik & Straume (“Sick Children in the Family”, n.d.) divide the term “chronic illness” into two categories, chronic conditions and chronic, life-threatening illness. They state that chronic conditions are illnesses which one “does not recover from and will have a marked effect on everyday life,” and that chronic, life-threatening illnesses are “ones which can be serious and terminal,” (Hordvik & Straume, “Sick Children”, n.d., p. 8). They also comment that even if a child has a life-threatening illness that is terminal, medical treatment and palliative care may be able to extend the child’s life considerably.

### **What systems are there in place for families of children with chronic illness?**

Hospitalization durations can vary among children with different types of chronic illness, but most children with chronic illness require frequent check-ups, clinic visits, and surgical procedures, (KidsHealth, n.d.). Although a chronic illness such as cancer creates different health concerns than spina bifida or cystic fibrosis, families may experience similar challenges or situations within the medical field and within their family systems.

Children with chronic illness are typically treated at pediatric hospitals.

Minnesota is home to several hospitals that specialize in pediatric illness including Gillette Children’s Specialty Healthcare, Children’s Hospitals and Clinics of MN, the University of Minnesota Amplatz Children’s Hospital, Mayo Eugenio Litta Children’s Hospital, and the Shiners Hospital for Children. It is rare that a child would be treated at a hospital not specifically for children, however some children are able to visit nearby

hospital or clinics that are more convenient for the family for frequent procedures such as chemo therapy.

According to the Children's Hospital of MN (2012), Gillette Children's Specialty Healthcare Hospital (2013), and the University of Minnesota Amplatz Children's Hospital (2013) there are several systems in place at the hospitals to support families dealing with chronic illness. For example, social workers are on staff to help patients and families adjust to new diagnoses or injuries, coordinate their care, cope with life and health transitions, and locate community resources (Gillette Children's Hospital, 2013). Child-life family services are available to make the child's hospital experience less stressful by providing therapeutic play, tours of the facility, medical play sessions to increase awareness of the medical procedures, and activities that promote healing and socialization (Amplatz Children's Hospital, 2013). Psychology, psychiatry, and neuropsychology staff are also on staff to provide mental health services for adjustment issues or management of chronic illnesses (Children's Hospital, 2012). Most hospitals that attend to pediatric illness offer these services. Some grief support groups for parents and siblings, oncology support groups for parents, and parent-to-parent support groups were also identified by the institutions, (Children's Hospital, 2012, Gillette Children's Hospital, 2013, Amplatz Children's Hospital, 2012).

### **Evidence of Effects on Families with Ill Children**

Battle (1975) and Steele (1977) identified that common stressors from living with and caring for a child with a serious illness include things such as the child's daily care, financial stressors (such as the cost of treatment), trips to the hospital or clinic, the care of siblings, changes in the family routine and in the family dynamics, the uncertainty of the

situation, and differences in how each family member copes, (Menke, 1987, p. 132). The effects and needs of immediate family members can vary. The immediate family members can be divided up into three groups: the children who have the chronic illness, the parents, and the siblings.

**Evidence of effects on chronically ill children.** Children experiencing a chronic illness are bombarded by changes that are directed by others. During this, the process of normal childhood development is often disrupted. (Frels, Leggett, & Larocca, 2009). Being diagnosed with a life-threatening illness can be traumatizing for a child. When a medical illness strikes, the child's physical activities may be limited, their social interaction time with other children is disrupted, and it can alter their psychological development of self. Not only can an illness feel isolating but "dependence on parents is a natural consequence because parents are a necessary source of sympathy, a buffer and support for their children," (Sick Children in the Family, n.d., p. 13). The psychological burdens of having a chronic or severe illness can also cause concentration problems, difficulties at school, and school absences which can affect a child in a long term sense, (Sick Children in the Family, n.d.).

Despite the setbacks, Hampel, Rudolph, Stachow, Lab-Lentzsch, and Petermann (2005) referenced studies suggesting that the children with chronic illnesses have abilities to cope with common stressors and illness-related stressors are "enhanced rather than impaired", (p. 146), compared to non-chronically ill children and adolescents. Perhaps this is due to the adaptability and resiliency of children. In support of these findings, when focused on children with asthma, atopic dermatitis, and cancer, Hampel et al. (2005) also found that coping with everyday stressors was improved for children with

chronic illness. The patients reported less passive avoidance coping and instead used more situation-specific coping and use of cognitive coping strategies, (Hampel et al., 2005).

***Age and gender.*** However results vary by age. Adolescents from ages 13 to 15 years old, with a chronic illness, run a high risk of developing psychological maladjustment due to lack of coping capacities, possibly because stressful events increase for most in early adolescence, (Hampel et al., 2005). Somewhat contradictorily, Mussatto (2006) reports that adolescents in the same age range with chronic illness, such as congenital cardiac disease, have lower anxiety and greater superego strength, but that pre-adolescents who are a bit younger, report poorer body image and self-concept. Results have also demonstrated that girls are more prone to poor coping and also belong to risk populations for psychological malfunctioning within this population, (Hampel et al., 2005). Girls tended to rely on more social support systems than boys, (Hampel et al., 2005). Little research was found specifically on younger children's experiences by gender.

***School disruption.*** There are important distinctions for children who are diagnosed with an illness at a very young age, for example before they've started school. The majority of their time will have been spent around other adults (doctors, nurses, hospital workers, etc.). The transition to school can be a stressful one; this may be the first time that the child notices differences between himself and other children his age, (Melnik, Moldenhouer, Feinstein, & Small, 2001). There may be differences in appearance due to the illness and treatments or differences in social skills, (Melnik et al.

2001). It is important that the school staff is aware of these challenges. They should be aware of these challenges if an older child has missed a substantial amount of school.

**Evidence of effects on parents.** Although the average parenting role includes *some* worry, Coffey (2006) states that “the parents of children with chronic illness have worry as a bona fide part of everyday life,” (p. 53). In a study examining the mental health of mothers caring for children on ventilator assistance, Badr & Kuster (2006), found that the variances of parental stress measurements usually start with two factors; the functional status of the child and the impact of the illness on the family. The family experiences more stress if the child’s functional status is low and experiences more stress if the impact of the illness is high (Badr & Kuster, 2006).

However, according to Brehaut, et al. (2009) “Caregivers who feel *burdened* by caring for children with relatively *mild* conditions may fare more poorly than caregivers who feel *less burdened* by children with more *severe* health problems, (p. 1258). It may be the “perceived severity” rather than the actual severity of the child’s health problem that affects the caregiver’s health more, (Brehaut, et al., 2009). Therefore, while the functional status of the child plays a role, the feelings and experiences of parents are contextual and can vary based on personal perspectives, and in turn will affect them in different ways.

Parents can experience anxiety if their child’s illness has gradually developed over time, (Sick Children in the Family, n.d.). It is normal for some parents to experience “relief” when a diagnosis is made for the child because that gives them a plan for what to do next in terms of treatment. Other parents may feel shock and disbelief after a diagnosis is made, (Sick Children in the Family, n.d.). Parents report that their initial reactions are

commonly filled with confusion, emotional turmoil, anger, and devastation, (Jerrett, 1994). “The anger could be directed at almost anyone—the doctor, God, each other,” (Jerrett, 1994, p. 1053).

The time of the child’s initial diagnosis is reported to be the most frequent time when parents have experienced grief, (George, Vickers, Wilkes, & Barton, 2006). Research has shown that grief experienced by the parents is multi-sourced and that dealing with health professionals during a time of grief can be especially aggravating for a parent, (George et al., 2006). Parents of a child who has been diagnosed with a life-threatening illness, may find that they start mourning for their child. This is called anticipatory grief, (Sick Children in the Family, n.d.). George et al., (2006) found that ten out of twelve parents report experiencing chronic grief, defined as “pervasive sadness that is permanent, periodic, and potentially progressive in nature,” when their child is experiencing a chronic illness, (p. 234). Interestingly, parents also report that grief is triggered by factors such as hurtful comments from other people, being asked to repeat the child’s condition, hearing stories about death, the deterioration of the child’s health, and uncertainty when going for tests and medical appointments with their child, (George et al., 2006, p. 234).

After dealing with the emotions of the initial reaction and coming to terms with the diagnosis, parents then spend some time struggling and learning how to manage their child’s illness on a daily basis, (Jerrett, 1994). Parents also experience consequences. It is important that parents develop tolerance and the ability to cooperate amongst the stressful situation. It is normal for mothers and fathers to react differently though, (Sick Children in the Family, n.d.). Women tend to worry more and dwell on questions and thoughts

about the child, while men tend to keep their difficult thoughts at a distance by keeping busy, (Sick Children in the Family, n.d., George & Vickers, 2007). In addition, men are less likely to perceive social supports in the environment as an option, (Ferran, 2986). There is not much research on interventions with couples who are dealing with a chronically ill child. However, Emotionally Focused Therapy (EFT) has been found to produce significantly higher scores in marital adjustment on the Dyadic Adjustment Scale (DAS), which is a self-reported measure of relationship adjustment, (Walker, Johnson, Manion, and Cloutier, 1996).

**Evidence of effects on siblings.** The effects on the siblings of terminally or chronically ill children is least researched of the three populations. Farber (1964) and Futterman (1973) proposed that:

The stress and upset that is experienced within the family are likely to have ramifications throughout the family system, causing shifts in the way family members interrelate, having an impact on the child's behavior, and placing the family members at risk for emotional problems," (as cited in Lavigne & Ryan, 1979, p. 616).

Menke (1987) found that the majority of school-aged children who had siblings with chronic illness expressed worry about them, especially those with diagnoses that are potentially fatal. The study also found contradictions to previous studies in which negative *behaviors* were identified in siblings, (Lavigne & Ryan, 1979; Menke, 1987). Menke (1987) discovered that parents reported few behavioral problems with their children who had an ill sibling. Menke (1978) also suggested that the coping patterns of



the parents may influence how the siblings cope, but no data was obtained about the parental coping styles in the study.

On the contrary, according to Anderson & Davis (2011), siblings of chronically ill children have been found to have higher rates of psychosocial problems including psychological issues and behavioral issues. In this study, siblings experienced higher rates of anxiety, emotional regulation problems, discipline problems, and problems with peers, (Anderson & Davis, 2011).

The siblings in the family are often the last to find out about the illness and tend to be an overlooked group, (Sick Children in Families, n.d.). When less time and attention from immediate family is available, and less concern is shown from other family and friends, for the siblings, feelings of jealousy and thoughts of being loved less can arise, (Sick Children and Families, n.d.) Even children who understand the illness and who understand that the sick child needs more time and support can have these feelings and it can be very troublesome for them, (Sick Children and Families, n.d.). According the Anderson & Davis (2011), the loss of parental attention and feelings of anxiety and guilt are a big stressor but other stressors that have been found as well. These include shifts in roles and expectations, concerns about the cause of their sibling's illness, social isolation, and avoidance of disclosure within the family, (as cited from Madan-Swain, Sexson, Brown, & Ragab, 1993). These findings suggest that siblings of chronically ill children should be primary data sources to gain additional insight into their experiences.

### **Coping Strategies**

According to Lazarus & Folkman (1984), coping is defined as constantly

changing cognitive and behavioral efforts used to manage specific external and internal demands that are beyond the resources of the person, (as cited in Melnyk, Moldenhouer, Feinstein, & Small, 2001, p. 650). The two primary functions of coping are regulating emotional responses and solving problems, (Melnyk, 1984). When measuring how well family members are coping with the experience of a child being chronically ill, both the level of emotion and degree of functioning should be assessed.

Research in the social work, psychology, and medical fields have found a variety of different coping methods and patterns used by family members with chronically ill children. These coping methods are both positive and negative. Some examples of the predominant coping strategies are as follows: generalized self-efficacy (a belief that one has the capabilities to control their life), emotion-orientated coping style, focusing on family cohesion (family unity), seeking social support, escaping or avoiding the situation, focusing on specific problems at hand, seeking a distraction from the stress, blaming or directing anger towards someone else, simply managing daily care, taking advantage of community resources, giving meaning to the illness, turning to religion, focusing on the positive aspects or accepting, worrying, expressing emotions, controlling emotions, withdrawing socially, compromising or negotiating, being open and flexible about the situation, and letting go, (Sherman & Simonton, 2001; Brewer et al., 2007; Hampel et al. 2005; Frels, Leggett, & Larocca, 2009; Cosby et al. 2007; Hovey, 2005)

According to McCubbin et al. (1983), the coping patterns that parents appear to find value in the most are:

“(a) maintaining family integration, cooperation, and an optimistic definition of the situation; (b) maintaining social support, self-esteem and psychological

stability; and (c) understanding the medical situation through communication with other parents and consultation with the medical staff,” (p. 328).

Stress is prominent among families caring for an ill child. Badr & Kuster (2006) state that the mediators of stress are coping and social support, while the manifestation of stress can be depression. Although social support can be considered *as* a coping device, some specific helpful *ways* of getting support were discovered by Brewer et al. (2007) when looking at the effects of Juvenile Huntington’s Disease on family members. The social support found to be most helpful consisted of the following: others listening and believing in the family, others being flexible, the support being consistent over time, and doctors being honest with the family (Brewer, et al. 2007, p. 44). The unhelpful support came from any of those contradictory actions and anyone trying to blame the condition on one factor, (Brewer et al., 2007)

It was mentioned above that “perceived severity” by the caregiver can affect the caregiver’s mental health (Brehaut et al., 2009). Lightsey & Sweeny (2008) found that persons who attach a meaning are more likely to tolerate the stress and are able to utilize more coping skills. Meaning refers to being able to attach a reason or explanation to the child’s diagnosis. For example, some parents may attribute that a higher power had a reason or that the illness has brought the family closer together. In alliance with that, Sherman & Simonton (2001) also suggest that finding meaning and enhancing family cohesion are ways to cope with cancer in the family. It is important for the family to feel united, to stay strong, and for everyone to feel included and as if they are in the battle together. Finding a meaning in the conditions such as “this is a way for us to grow closer” or “this is a reminder as to what is really important in life” is another positive way, that

was found, to cope (Sherman & Simonton, 2001, p. 198). Another way to find meaning is to participate in research or pursue a dream for the family. Any family that finds meaning by saying something negative like “our family sinned too much and now God has abandoned us” should be directed to look at how others see the situation. Then, in order to reduce stress, the goal for the family would be to reconsider and experiment with more flexible and adaptive meanings. (Sherman & Simonton, 2001).

**Hope as a coping strategy.** Hopeful thinking is found to play a significant part in influencing movement towards a family’s goals and perceived ability to do so. The research shows that, childrens’ (and parents’) hope scores are, not surprisingly, lower when the child is experiencing a chronic illness, (Venning, Elliott, Whitford, & Honnor, 2007). In addition, results partially supported that “only self-efficacy and depression contributed to the hope scores of children,” (p. 719). Neither belief in God, anxiety, number of friends, nor the time since diagnosis, contributed to the hopes scores (Venning et al. 2007). This suggested that perceived self-efficacy is important to hopeful thinking when a child faces a chronic illness as it “enables them to set goals, facilitates adherence to treatment schedules, and keep them energized to achieve goals in difficult situations,” (Venning et al., 2007, p. 721).

**Time-Management.** Another coping skill is time-management. Parents report the need to control time by diligently becoming organized in all aspects of life, (George et al., 2006). Re-organization and working out a schedule allows parents to carry out their family responsibilities, (George et al., 2006, p. 1054). The re-allocation of tasks is often stressful, but eventually the parents feel more capable, as they are able to focus their energy and attention, (George et al., 2006).

**Caregiver gender.** There are differences in coping strategies among mothers and fathers. Lightsey & Sweeny (2008) found that women more frequently used emotion-oriented strategies to cope with chronic illness of a child and that women who used less emotion-methods experienced higher family satisfaction. Their findings suggest that “reducing mothers’ reliance on maladaptive, emotion-orientated coping strategies may be quite important in augmenting the family satisfaction” (p. 219). Fathers, in particular, use four positive strategies to cope most effectively. They include problem solving techniques, looking at options, getting information, and weighing choices, (Hovey, 2005). The fathers often perceived their wives to be more concerned about burning out and the fathers also perceived the mothers in the roles of taking responsibility and caring for the family. The mothers are often seen as the primary caregivers in the families by fathers, (Hovey, 2005). However, this study suggested that fathers do have concerns about doing activities together as a family, about making sure that their family is happy and comfortable, about talking with and understanding their families, and about having enough fun and relaxation, (Hovey, 2005). Another study shows that fathers are the least likely of the family members to perceive social supports in their environments, (Ferrari, 1986). However, mothers of children with chronic illness also perceive social supports to be lower than mothers with healthy children, (Ferrari, 1986).

**Real vs. perceived isolation.** Ferrari cites research that suggests that seriously ill and dying children often experience intense feelings of isolation and loneliness. It is likely that, for families with a handicapped child, the family members may also be susceptible to these feelings, “both as a function of their perceptions of support in the environment and the degree to which the support network actually does respond to the

family's needs," (p. 28). This ties in with the fact that parents of chronically ill children have been documented to report higher levels of burnout symptoms than parents of healthy children, especially mothers, (Lindström, Åman, & Norberg, 2010).

**Other risk factors.** Risk factors for poor adaption of positive coping skills can also result from different demographic circumstances. According to Hentinnen & Helvi (1998), parents with sufficient personal and social resources, advanced levels of education, higher levels of income, and having only one child to care for, adapt better than those with poor resources and lower levels of education and income, (p. 317).

One example of a resource that has been found to be helpful is overnight camps for chronically sick children, (Meltzer & Johnson, 2004). Although the primary purpose is to provide a feeling of normalcy for the children, it can be seen as a form of respite for the parents. According to Meltzer & Johnson (2004), mothers' overall psychological functioning improved while their chronically ill children were at camp. While care giving demands returned to normal when the child returned, they were diminished while the child was gone and a few mothers' reported that their relief was maintained for up to 1 month after camp.

It has also been found that the child can influence how the parents cope. In a study examining parental coping with a child who has Sickle Cell Disease (SCD), a family member said that she relied more on what the child was telling her versus what she was seeing to know how the child was feeling or how she should react (Cosby et al., 2007). Thus, if the child explained that she was not scared or worried a lot, the family member was more at ease.

Young children who have chronic illness have been shown to cope well when creativity is combined with solution focused therapy, (Frels, Leggett, & Larocca, 2009). Descriptive studies have shown that chronically ill children have been able to personalize strategies to deal with painful procedures and metaphorically eliminate situations that they do not enjoy when using a form of play therapy while searching for solutions to problems, (Frels et al., 2009). This is an important part of what child-life specialists do in children's hospitals to help children cope, (Children's Hospital, n.d.).

The most common coping strategies that have been proven to produce positive effects among family members include, receiving social support, associating a higher meaning with the child's condition, accepting the condition or focusing on the positive, focusing on family cohesion, and seeking distraction, (Coffey, 2006; Ferrari, 1986; Fisher, 2001; George et al., 2006; Hallström & Elander, 2007; Hampel et al., 2005; Jerrett, 1994; Lavigne & Ryan, 1979; Melnyk, Feinstein, Moldenhouer, & Small, 2001; Menke, 1987). The most common strategies that either produced negative effects or did not help at all were blaming the situation on someone else, withdrawing socially and going into isolation, worrying, and feeling hopeless and letting go. (Coffey, 2006; Hampel et al., 2005; Hentinen & Helvi, 1998; Hovary, 2005; McCubbin et al., 1983; Menke, 1987).

Through a critical review of study results, Anderson & Davis (2011) discovered that four types of practices were used the most when providing interventions for families with an ill child. These included disease specific educational training, stress point interventions, problem solving training, or therapeutic interventions, but not many of these practices developed actual coping skills within the family, (Anderson & Davis,

2011). Most of these practices were not randomized or systematically reviewed studies, but instead, were controlled studies, descriptive studies, case studies, and reports of expert committees. It would be helpful for families to experience evidence-based practices that help with specific stressors that have been identified throughout the literature.

In conclusion, the research has shown that the effects of having a chronically ill child in the family can produce a variety of responses in the family. The family dynamics are affected in several ways and a variety of coping strategies are used. However, the research provides little information on how professionals can advance or extend their knowledge to be most helpful to the families experiencing the crisis.

### **Conceptual Framework**

In this section, the conceptual framework of several theories will be applied to the research. This writer found the resiliency theory, the strengths perspective, the family systems theory, and the childhood stages of psychosocial development to be the most applicable and effective when researching in the area of families with chronically ill children.

#### **Resiliency**

The first theory that is applicable to this research is the resiliency model of adjustment and adaptation of the family. In this case, resiliency can be defined as

The positive behavioral patterns and functional competence individuals and the families demonstrate under stressful circumstances, which determine the family's ability to recover by maintaining its integrity as a unit while insuring, and where



necessary; restoring, the well-being of family members and the family unit as a while, (as cited by McCubbin, 1996 in Musatto, 1997).

According to Packer & Mork (2014), resiliency is the ability to recover and adapt quickly from change, misfortune, or difficulty. They also noted that resilience is not a characteristic which some have and some do not, rather it is something that is developed. Packer and Mork (2014) say that some factors related to resilience include having meaningful relationships with others that are resilient, being able to manage strong feelings and impulses, having a positive self-image, having a hopeful outlook, and having a sense of humor.

The resiliency model says that highly resilient families are more likely to progress quickly, and have better outcomes than families with fewer resiliencies. Families that have successfully coped with difficult situations in the past can be guided to draw from those experiences to find the strength to make it through their current situation. There are several factors that can influence the perceived resiliency including age of the child, gender, ability to comprehend the illness, the onset of the condition, level of severity, predictability of symptoms, prognosis, the families experience with stress, traits of anxiety within the family members, systems of support, and culture, (Musatto, 1997).

### **Strengths and Empowerment**

Another theory that can be applied to this research is the strengths perspective. This perspective is a well-known, social work based perspective that focuses on the client's strengths and attributes, rather than the weaknesses and negative aspects. This model is executed by using collaboration between the worker and the client or family to discover positive points and successes to promote motivation within the client. This

perspective affirms that clients know their situation best and when given options, can determine the best solutions for challenges, (Miley, O'Melia, Dubois, 2013). This perspective also recognizes that each client has the capacity for growth and change and that this change can be built with a vision of future possibilities, (Miley et al., 2013).

The strengths perspective fits nicely together with the empowerment approach because pointing out strengths within families will empower them. Personal empowerment is built from competence, the client's state of mind, and the feeling of having some control. Because families experiencing the crisis of having a chronically ill child can often feel debilitated and powerless, it is important for social workers to instill a sense of control over some of the situation. Families can be empowered by being connected with resources and creating goals to diminish feelings of helplessness.

### **Family Systems**

Family systems theory is also helpful when working with families with chronically ill children. "Family systems theory is a theory of human behavior that views the family as an emotional unit and uses systems thinking to describe the complex interactions in the unit," (The Bown Center, 2013). According to this theory, the nature of a family is that its members are intensely connected by emotions and patterns. The child's illness affects the entire family and the family dynamic, therefore it is helpful to look at how each person in the family experiences the situation and then at how they interact and influence each other. The system, in turn, affects each of the family members as well. The family system is interdependent. The family system interacts in patterns, using the knowledge of boundaries and messages to maintain the family's equilibrium. In

a family with an ill child the equilibrium is disrupted and new messages, boundaries, and patterns must be established.

### **Childhood Stages of Psychosocial Development**

The final theory that plays a part in the research of families with chronically ill children is the conceptual framework created by Erik Erikson that outlines the psychosocial stages of development across one's lifespan. This theory states that children and adults have eight basic developmental challenges and important stages that happen throughout their lives in certain stages.

The theory states, children from birth to infancy are developing a sense of trust when caregivers provide a sense of reliability and affection for them. A lack of this can cause mistrust towards the outside world. Children in the early stages of childhood, from ages 2 to 3, are in the process of developing physical skills and independence which can lead to feelings of either autonomy or shame and doubt. In the preschool years, from ages 3 to 5, children are exploring their world and trying to find a sense of purpose. Preschoolers are in the stage of initiative vs. guilt. Older children, who are ages 6 to 11, are learning to cope with social and academic demands in which they might succeed, feeling competent, or fail, feeling inferior. This stage, or sometimes referred to as conflict, is named industry vs. inferiority. Adolescents, from ages 12 to 18, are in the process of developing a sense of personal identity and if this is weak, can lead to feelings of role confusion. The last stage that applies to the population in this study are the young adults, from ages 19 to 40, who experience success by forming intimate and loving relationships, while failure to form strong relationships results in isolation.

The theory describes two later stages of life as well, but the earlier stages are the most important when examining children and adolescents with chronic illnesses. The diagnosis and turmoil of a chronic illness can interfere with a child's development within these stages of life and can cause important developmental achievements and natural psycho-social stages to be put on hold. The child with chronic illness may progress through the stages later than the average child, which can result in psycho-social delay.

In conclusion, the resiliency theory, the strengths perspective, the family systems theory, and the childhood stages of psychosocial development are the conceptual frameworks that are the most important to apply when working with families with chronically ill children.

## **Methods**

### **Design**

This research was an exploratory, qualitative research design. The purpose of qualitative research is to gain insight into life experiences and give meaning by using a systematic subjective approach. This research aims to discover the complex and broad range of interpretations and experiences of families with chronically ill children or children that have chronic medical conditions, to explore the implications, and to develop grounded theory through family case studies.

Holistic and exploratory interviewing was used to gain an understanding of the experiences of family members. This method allowed for more in-depth information to be gathered than a quantitative study. The steps included collecting the data, analyzing the data, and using this information to find themes within the data to draw conclusions.

The interviews were semi-structured in format so that important information could be explored further.

### **Sample**

This researcher conducted 5 interviews with mothers, fathers, and caregivers of children with chronic illnesses. The participants were recruited using a non-probability sampling strategy known as snowball sampling. This strategy involves recruitment of readily available subjects in the twin cities area. After a connection was made with potential contacts of these parents, they were asked to pass along the information to possible participants, who meet the criteria, through personal referrals. Informational flyers, e-mails, and word of mouth were also used to recruit the participants. Flyers were displayed in public areas such as libraries, grocery stores, coffee shops, malls, hospitals, counseling centers, and campus bulletin boards in the St. Paul/Minneapolis area and its surrounding suburbs (see Appendix A). E-mails were sent to social work departments at clinics and hospitals and to counseling centers. These were researched online. The information was also spread using social media and word of mouth. All fliers, e-mails, and social media references included a request to pass the information on to anyone who might be interested.

The participants had to be over the age of 18, must have a child with a chronic illness for whom they are a primary caregiver, or have experienced having a child with a chronic illness for whom they were a primary caregiver in the past.

### **Protection of Human Subjects**

In order to protect the human subjects that were interviewed in this research study, client confidentiality was addressed in several ways. First, the project was

approved by the University Institutional Review Board. Prior to the interview each participant was spoken to on the phone, read the phone transcript (see Appendix B), and were provided with the informational sheet to read (see Appendix C). The participants signed a consent form stating the procedures, risks, benefits, voluntary nature, and rights in order to participate (see Appendix D). The consent forms were kept in a secure file cabinet in the researcher's home. The interview took place in a closed room. The audio files were kept on the researcher's private audio recording device which was also kept in a secure file cabinet in the researcher's home. Only the researcher had access to the audio files for the purpose of content analysis. There was no transcriber or research assistant other than the researcher, so the confidentiality agreement was not needed (see Appendix E). The audio files were erased by the researcher after the completion of the research project.

Due to the psychological distress that may have risen within the participants during the interviews, resources for counseling were provided to the participants, such as the Interprofessional Center (IPC) at the University of St. Thomas (see Appendix F). If at any time during the interview, the participant appeared to be experiencing psychological or emotional distress the interviewer asked if the participant would like to stop or take a break. Each participant was informed that they may voluntarily pull out of the research study at any time and that there would be no repercussions.

### **Data Collection**

After the participants contacted the researcher, an information sheet was sent by e-mail. The participant was informed of the consent form and was asked to pick a location with a private room to conduct the interview. A private room at a local public

library or at the University library was suggested. The interviews took place in private rooms within libraries, coffee shops, offices, and in the participants' homes. Upon meeting each participant, any questions that the participant had were addressed and the consent form was provided to be signed. After the signature was obtained, a list of the interview questions was provided to the participant. A digital audio recording device was used to record the interview. The interview followed the structure of the interview questions for the most part, only diverging if clarification was needed or if further exploration was warranted (see Appendix G).

### **Data Analysis**

This researcher analyzed the data and used grounded theory to organize and interpret the data collected. The audio recordings of the interviews were transcribed and the participants were given pseudo names so that their identities could be kept confidential. Key points from the text were marked and grouped into similar concepts so that categories could be formed. Using these categories, the theories arrived. This allowed the researcher to identify major themes across the data set. Grounded theory uses the data to develop a common theme, or hypothesis, from the collected data, rather than searching for information to support a pre-determined hypothesis, (Monette, Sullivan, & DeJong, 2010). Each interview was analyzed to find similarities and differences in opinions.

### **Strengths and Limitations**

This research study will provide valuable information to the clinical social work field pertaining to families dealing with the crisis. Social workers can come to a better understanding of how families view professionals during this time and what is most

helpful to their needs. The qualitative design allows for a deeper understanding of the participant's story and what the experience is like for them. The semi-structured interview allows for the similarities and differences to be found across families by comparing the common questions, yet were not rigid, allowing the researcher to explore specific information presented by the participants. This allows for greater understanding and for unprompted areas to be explored.

The exploratory nature of the study limits the ability to generalize the findings to larger population, however. The majority of the participants were from the St. Paul/Minneapolis area in Minnesota, which also narrows down the applicability. The number of participants interviewed also affects the ability to generalize the findings. Because this is such a sensitive topic for caregivers and parents to volunteer to talk about, and because families in this situation are often experiencing crisis, the criteria to meet the study's standards had to be left open concerning the types of illness that the child may have. This was done purposely so that the researcher would be able to recruit enough participants and also so that themes might be found across families regardless of the type of illness that the child is experiencing.

The sample for the study was recruited using snowball sampling, which is not randomized and limits the diversity among the participants. Future studies should be randomized in recruitment and should involve more participants.

Finally, the study was conducted and analyzed only by the primary researcher so the findings may contain biases that were overlooked.

## **Conclusion**

The research study is a qualitative in design so as to discover the effects and



successful interventions or coping strategies within families who are caring for a chronically ill child. The participants were recruited, informed of their rights, and asked to consent to the parameters of the research study, which is voluntary in nature. The research findings were analyzed and synthesized to discover common themes so that social workers may use the information to further benefit families in similar situations.

### **Findings**

The purpose of this study is to examine the impacts of having a child with a chronic medical condition or medical illness within the family and to find out how social workers can be of more service to them. There are many factors that contribute to the effects and outcomes. To explore these factors I asked questions pertaining to the family dynamic before their child was diagnosed, pertaining to what's been hardest for them throughout the experience, how they've been able to cope and what they have found to be helpful, and what their experiences with hospital professionals and social workers has been. Each participant was assigned a number and, for confidentiality purposes, the researcher has given each participant and their child pseudo names that can be found in the demographic display table (Table 1) below.

### **Demographics**

As displayed in Table 1, the interviewees included 2 males and 3 females. All were primary caregivers of a child with a chronic illness or medical condition; this included mothers, fathers, and a step-mother. Participant 5 has a child who is presently a young adult, but the information that was gathered was pertaining to the height of the illness, when the child was young, so the demographic information reflects the father's

marital status, income, and living area for that time period of his life. The caregivers' ages ranged from mid-20s to mid-40s and the children's ages ranged from 10 months old to 11 years old. All of the children with the illnesses or medical conditions were male. And all of the children received medical care from a pediatric hospital in Minnesota. Most of the caregivers were Caucasian, while participant 1 identified as African American and Hispanic. Most of the families had 2-3 children living at home, while participant 5 had 8 children. The education levels of the caregivers ranged from High School to Master's Degree, with 3 of the participants having a Bachelor's Degree. Participant 1 was self-employed, participant 5 was a stay-at-home father, and the others were employed outside of the home for wages. The yearly household incomes for the families ranged from the \$25,000-\$49,000 bracket to the over \$125,000 bracket and the families lived in a variety of settings, with 3 of the 5 reporting to live in a rural setting.

Table 1.

*Demographic Information for Study Participants*

Particip. Number	Pseudo Name	Relation to Child	Child's Pseudo Name	Marital Status	Racial/Ethnic Identity	Number of Children living in the home	Education Level	Employment	Yearly Household Income	Living Area
1	Kate	Mother	Easton	Never Married	African Am. & Hispanic	2	High School	Self-Employed	25,000 – 49,999	Urban
2	Ann	Step-Mother	Ryan	Married	Caucasian	3	Master's Degree	Employed	125,000+	Rural
3	Tim	Father	Kevin	Married	Caucasian	2	Bachelor's Degree	Employed	75,000 – 99,999	Rural
4	Linda	Mother	Brandon	Married	Caucasian	2	Bachelor's Degree	Employed	75,000 – 99,999	Rural
5	Jake	Father	Isaac	Married	Caucasian	8	Bachelor's Degree	Homemaker	50,000 – 74,999	Suburb.

**Introduction to Data**

Many themes were found across the data. They have been categorized into 3 main sections that include negative impacts and challenges for families, positive impacts and

coping strategies for families, and social work based themes. The sections on negative and positive impacts are further divided into 3 categories based on the population type including the parents, the child with the medical conditions, and the siblings. These categories contain several subcategories that include detailed information from the participants' interviews. While many of these impacts can be applied to social work and other medical professional services, the last section titled social work themes includes information and suggestions from interviewees that did not fit well into the positive and negative impacts, but were applicable to the social work field.

Prior to the sections that include the themes, mentioned above, is a section below that provides some background information about the diagnoses of the children whose caregivers were interviewed.

### **Types of Illnesses and Medical Conditions in the Children**

Participant 1, nicknamed "Kelly", reported that her 4 year old son, nicknamed "Easton", has a condition considered tracheal stenosis. While in the womb, 2 mm of Easton's air way stopped growing and hardened. He was not able to breathe at birth and has undergone several surgeries. He is left unable to speak with acid reflux that continually irritates the scar tissue in his tracheal tube, which they are awaiting to be removed.

Participant 2, nicknamed "Ann", reported that her step-son, nicknamed "Ryan", has the primary diagnosis of 18 Q Syndrome, which is a rare chromosomal disorder. He also has a seizure disorder, cerebral palsy, developmental delays, a swallowing disorder, and he is completely dependent on others for everything. He is immobile and cannot

speak. She reports that he was only expected to live until age 6, and now he is age 11. He was diagnosed as a baby.

Participant 3, “Tim”, chose to provide information about his son, “Kevin” from the period in his life when Kevin’s cancer was most prevalent. Kevin was diagnosed with bilateral retinal blastoma, a form of cancer in the eyes, at the age of 10 months. He lost all vision in his right eye, because it was consumed by tumors, and went through 22 months of chemotherapy to save the vision in his left eye. Kevin is currently 26 years old and in remission, but his father focused on the years of chemotherapy throughout the interview.

Participant 4, “Linda”, reported that her 3 year old son, nicknamed “Brandon” has severe hemophilia B. This is a rare bleeding disorder in which the blood does not clot normally. Brandon has less than 1% of something called clotting factor IX, which is a clotting agent that is needed in the blood. He can experience spontaneous bleeding, bleeding in the joints, or bleeding in the brain which is a serious complication of hemophilia.

Participant 5, “Jake”, reported that his son, “Isaac” has been admitted to the hospital 35 times from 2 to 80 days in his 4 years of life. Isaac was born with mosaic Trisomy 21, which means that about half of his cells have the normal amount of chromosomes, and the other half include the extra number 21 chromosome, causing the mosaic Down syndrome. He also has an unbalanced atrioventricular (AV) canal defect in his heart, which means that the wall is gone for the 4 chambers of the heart and the blood would keep cycling in one area. He also has a condition called F-PIES which stands for Food Protein Induced Enterocolitis Syndrome, which is a mediated immune reaction in

the gastrointestinal system to specific foods. Issac is allergic to protein and when he did have protein in his body, as an infant, his body produced colitis (an inflammation of the large intestine) then he went into septic shock and had a stroke. Isaac also has an immune deficiency that can cause him to become very sick very quickly.

These are all very serious medical conditions. The caregivers were able to provide detailed information as to how they've been impacted by these diagnoses in their children. In the next sections, the data from the children's caregivers' interviews were compared to one another to find themes that were common among the families. The themes are mostly divided up into two categories titled 'negative impacts and challenges for families' and 'positive impacts and coping strategies for families' with a couple themes in another section that applies strictly to the social work field. The sections including 'negative' and 'positive' impacts are further divided up into categories based on population including the parents, the child with the medical condition, and the siblings. Several subcategories are used to label each theme.

### **Negative Impacts and Challenges for Families**

**Parents.** Many themes arose across the data concerning challenges and barriers for parents of children with chronic or terminal medical conditions or illnesses. Some of them pertained to more individual experiences, such as seeing their child suffer or fearing that they might hurt their child more, and some pertained to external experiences such as feeling that medical professionals aren't listening to the them, the parents.

***Initial Reactions to Child's Diagnosis.*** First, the participants provided descriptions about their initial reactions to finding out about their child's chronic or terminal medical condition or illness. Participants reported feelings of shock, devastation,

disbelief, and fear. Participant 3 reported that his son was 13 months old when the cancer was found. He said, “When he was 13 months old we took him to the Regional Medical Center and they found the cancer and told us that we needed to take him to one of three places in the country.” After bringing their son to University of Minnesota he reported:

He explained that they couldn’t do anything to the right eye because it was too far gone... it turned out that he was in stage 4 cancer and his right eye was consumed by tumors. My wife dropped straight to her knees. Shortly after, we got to speak to an oncologist who was the most arrogant person in the world...

Participant 1 described her initial reactions to finding out that her son had tracheal stenosis. She reported that at first she didn’t understand because she had just had labor and was on medication, but that after she realized what was happening, she broke down.

Participant 4 described her initial reactions to finding out that her son had severe hemophilia. She stated that she “cried a lot...all the time...and was bordering on post partum depression.” She also felt like she wasn’t able to bond with her baby because she was so afraid that she would hurt him during the first month.

Participant 2 described that it was difficult for her husband to believe that something was wrong with his son. She reported that her husband’s past wife knew that there was something wrong long before the doctors did.

Participant 5 reported that when they first found out that their baby son had Down syndrome, that they didn’t think anything of it, but when they found out that their son might not live because of his heart condition they were sad but tried to accept it. He reported that they had a lot of big decisions to make about whether to try a risky surgery. He stated that at one point they had decided to bring him home to love him until he died,

but the surgeon said that he thought he might be successful, so they decided to go ahead and try.

***Seeing child suffer.*** All of the participants reported, either directly or indirectly, that it was hard for them to see their children suffer. This was an expected, but common theme. Participant 1 often made comments such as, “I feel so bad for him.” Or “It’s really tough to see him go through this.” Participant 3 described that it was hard to have to watch his son be put into a vice to hold still enough for the treatments. Participant 5 also reported that it was difficult to see his child in pain and to have to hold him down for the “pricks”. He said, “The hardest thing is seeing your child suffer by far.” Participant 5 also reported that this was very difficult for his wife when their son was a baby. He said, “For my wife, the hardest part at first was not being able to console him...because on a vent you can’t hold him and there are times you can’t touch him because it would stimulate the heart. It was a long time.”

***Fear of harming the child more.*** Parents expressed that after their child had been diagnosed, they experienced stress when handling their child, in fear of harming them. Participant 4 said, “The baby phase was the worst for me. I was scared of my baby. I felt like bonding with my baby was impaired at that time. The number one constant fear would be the fear of him getting hurt.” She stated that the fear of their son getting hurt is hard for her spouse also, along with administering his medication. Participant 1 also has a similar experience; she reported:

I think the hardest for me was when he actually came home [from the hospital]... that was the biggest thing for me because I was frightened of it. I thought I was going to do something wrong, even though he had nurses. The nurses were there

for 8 hours a day... I was super nervous to take care of him. I felt bad that I was nervous around my own son. I couldn't take him anywhere. He was so delicate... It was the toughest thing.

She also reported that it was also difficult for the father, stating:

My boyfriend has been in the picture for the last two years, but before that it was their dad. He had to completely change how he was with Easton. He was a real rough houser before. He wouldn't spend much time with Easton because he wasn't used to a kid that had problems. Every time Easton coughed, he'd have to rush to see what was wrong with him.

Participant 2 also reported that it's difficult to see your child in pain. She stated, "I think just watching your boy in so much pain [is what is difficult]. Ryan goes through pain cycles. So I think that his dad seeing him in that pain is really hard. We worry about his quality of life and his pain."

***Not having answers for others.*** A couple participants reported that it was difficult to not have answers. Participant 5 reported that it was stressful to not have answers for his children. He stated, "Having the other kids wonder if he's going to live or die...them worrying is hard for me. It's difficult to not have answers for my kids...not being able to tell them that everything is going to be alright." Participant 3 also reported that it's hard to have answers for others who expect and want to hear that everything is okay. Trying not to disappoint others is hard.

***Juggling work and medical care.*** Participants reported that it's hard for parents to manage their work lives and their child's medical needs together. Participant 4 stated, "One of the hardest things is having to oversee it all to make sure he gets the appropriate



care that he needs.” Participant 2 reported that it was hard for her husband and his previous wife to be in and out of the hospital all of the time to figure out what was going on with their son and that it caused a lot of stress on their entire family. And participant 5 reported, “Another struggle is that she is the breadwinner and she has a job...she’s at work and she wants to be at the hospital...and vice versa. It’s a struggle to get a job done and be at the hospital.”

***Guilt.*** A couple participants reported that they had some guilt about their child’s medical condition. Participant 3 talked about his wife’s experience. He said:

The hardest was the fact that the gene ran in her family. We were told that we didn’t have anything to worry about. The doctors would say we didn’t have anything to worry about and yet we ended up there. She absolutely had some guilt about it.

Participant 2 reported that her husband struggled for a long time because his wife, at the time, said that there was something wrong with their son, and he didn’t believe it. She stated, “His wife knew immediately that something was wrong with Ryan, but my husband was in denial for a while. The doctors didn’t know, but she knew. That was hard for him. There’s still some resentment there about that.” He struggles with knowing that he couldn’t see the condition early on.

***Lack of understanding and social support from others.*** Many of the parents expressed feelings of abandonment from their social supports and relatives due to the lack of understanding as to what they are going through.

*Relatives and friends.* Participants 4 stated, “My husband’s parents are afraid of the diagnosis; that’s hard to know that we don’t have great supports to give us a break.”

Participant 5 reported:

We thought our relatives would help out more. They didn’t. They didn’t understand what we were going through. For example, instead of taking our daughter for a day they’d ask us to drive her out to them...but if we got caught in traffic or got a flat tire our son would miss his chemotherapy appointment. And he couldn’t. They didn’t understand. My wife and I had to learn to rely on each other more. It taught us a number of things on how we can help other people out and we try to when we can.

Participant 3 also reported that it was hard when others didn’t understand the medical aspects. He said:

The other thing was dealing with folks who didn’t understand chemotherapy. They’d think he was fine after some treatments. They didn’t understand that it wasn’t like a broken arm where you treat it and it’s better. It’s an ongoing process until he’s 21 years old.

Participant 2 reported that she did not receive much support from her friends. She stated, “I do talk to my friends, but they don’t really get it... my co-workers have been more helpful because they’re speech therapists, teachers, and social workers.”

*Professionals.* Some participants described negative experiences with hospital workers. Participant 3 reported that he worked with an ophthalmologist who was not very sensitive about his son’s health issues. He stated:

He was the most arrogant man I ever met. When he marched in, he didn't say, 'Hi, I'm sorry, he didn't say anything but 'You folks need to know one thing only, and that's that your son has a 20% chance of saving any eyesight and a 50% that he's going to live to his 21<sup>st</sup> birthday' Again, my wife fell to her knees and I tried to hold on to her but I wanted to hit the guy. He could have started with 'I hate to break this to you but...' or 'I don't know how to tell you this but...' but right away he said it like Bang Boom! We were told that he was the best in the field but we said that we didn't care, and that we'd take the second best if he's more human.

*Families in similar circumstances.* Participant 4 reported that her husband doesn't benefit from connections with other families that she has made. She said, "It's mostly the moms who are connected. It would probably be more helpful to have a dads group." She thinks that he would benefit more from connecting with other parents of the same gender.

***Negative impact on marriage.*** Many parents reported that having a child with a chronic medical condition significantly impacts the marriage. Participants 4 and 2 reported some resentment about having extra responsibilities in their role concerning their child's treatment. Participant 4 stated:

Now we have a new medical world that we have to navigate. I primarily take care of the medical stuff. There are some hard feelings with my husband about that.

I'm always making the doctor appointments, ordering meds, and administering the medication. It can be hard to be the one having to remember to do everything.

Participant 2 discussed how her marriage has been impacted by her step son's illness and medical care. She stated:

In the beginning it was hard to figure out how I played into this, as the step-mom. Dealing with insurance issues and financial issues has kind've become my role, which I resent sometimes. Why am I the one who has to call the insurance companies when his formula doesn't come? Why is it always me?

Not only did Participant 2 report that it has affected her marriage in that way but she also reported that her step-son's illness was a large factor in her husband's previous divorce. She stated, "Prior to Ryan being born, they had two healthy kids. It was very hard on their marriage. They were divorced within three years and that was a big factor...a major part of their divorce."

Participant 3 reported that he had to be away from his family a lot because his wife and kids had to move into the Ronald McDonald house to be near the hospital for their son's treatment. He reported that it was hard to go home to an empty house each night, but that he had started a new job without vacation time, and he carried the insurance, so they "had to try it." Participant 3 also described that it was hard for his wife to be away from him as a support. He stated, "She didn't like being away from me and not having anybody to depend on there with her." Later, he also spoke about the his opinion of increased chances of divorce for families with an ill child. He said:

The divorce rate is 50% the way it is, but if you throw the death of a child or a critical illness in there, you can probably add about 20% more to that because there are so many marriages that don't survive because somebody wants to blame somebody.

Although participants 3 and 5 learned to rely on their spouses more than ever, they both reported that they often heard about divorces happening in other families from

the hospitals that their children received treatment at and said that it's very unfortunate that's it's so common. Participants 5 and 3 reported that they thought that more could and should be done to address the divorce rate and marital dissatisfaction among these families.

*Hard to navigate insurance and get appropriate, affordable care.* All of the parents reported frustration with their insurance companies and finances. Participant 4 said:

Our insurance is one negative thing because I'm so confused about who does what sometimes. There are too many people that are trying to handle it all. They are calling us all the time and we have to repeat the same things all of the time. I feel like it takes up my time. The financial aspect of it can be considered a stressor too because it's very expensive for his medication and the insurance can max out very quickly. We meet our insurance max every year.

Participant 1 also reported that navigating the health insurance system is difficult and stressful. Participant 2 stated that it's stressful to learn how to write appeals to the insurance companies. She stated:

The financial insurance issues are always super stressful, especially when you are denied and have to make appeals. It's hard to write a good letter and there are so many steps involved. Having someone walk us through the process would be helpful. We deal with 3 insurances, it's a lot sometimes.

Participant 5 also reported that financial issues and insurance issues can be stressful for his family.

***Medical professionals don't take caregivers opinions seriously.*** Many of the caregivers reported frustration with medical professionals in that they don't listen to their opinions about their child's health sometimes. Many reported feeling brushed off at one point or another because they are not medical professionals. Participant 1 told a story about explaining to the doctors that something was wrong with her son for 3 days at the hospital, being told to take him home, and then having to bring him back to be rushed into emergency surgery. She stated:

I remember being furious with them [the hospital workers] because I had told them that there was something wrong with my son. That was the most frustrating experience that has stood out in my mind in regards to the hospitals because I knew what was going on and they just didn't believe me. I think that they need to know that even though parents aren't the medical professionals that moms and dad know when something's not right...even when it's the littlest thing. I think they need to listen to what we say, even if it's something that might not mean anything, it is still something that we have noticed that has changed and it could mean something.

Participant 2 reported, "Getting the doctors to believe that there was something going on with my step son before they diagnosed him was a big negative for my husband and his wife." She later stated, "Believing that the parent knows their kid best is important. In most cases they are accurate reporters, so believing what they are saying is important."

***Seeing medical professional being unprofessional.*** Participant 5 reported that seeing nurse or other professionals behave or speak unprofessionally doesn't provide

much security. He also stated that when you are dealing with many different professionals that the quality of care can be very different person to person.

***Loss of other children in the hospital.*** Participant 3, whose family stayed in the Ronald McDonald house explained that the grief of other children dying is hard to cope with. He said:

The Ronald McDonald house was a Godsend to us... That wasn't a fun place to be either though. We were there for 7 weeks and 16 kids died that were staying there... there were twins where one died and the other one was still alive but knew what was coming. That was the saddest thing... and very hard for me.

Participant 5 also reported that the grief from seeing and hearing about other children dying is something that is challenging.

***Repeating our situation to professionals.*** Just as participant 4 reported having to repeat her situation to insurance providers often, other participants reported negatively about having to repeat their stories many times to hospital professionals such as social workers and nurses. Participant 3 said:

We had to repeat our story so many times when we'd go in because people wouldn't look in on why we were there. Every time we'd go in we'd have a new resident who'd say something like 'And what brings Kevin in today?' and we thought 'Look dummy, we're back for another chemotherapy treatment, ok? Did you not know this?

Participant 3 said, the biggest hunk of advice is to try and find out why people are there and if it's their first time or not. He said, "If they've been there a lot before, don't make them re-tell or re-live every episode." He also said that he would like to speak to the

public on the topic because that's how important it is to him. Participants 1 and 5 also reported that having to repeat the situation can be tiresome. They reported that this has become a very challenging factor for them.

***Home care is hard to get started correctly.*** Managing home health care nurses and personal care attendants are a cause of stress for many of the parents. Participant 4 stated:

The home health nurse was supposed to teach us how to access his port and I had no confidence in them. Nobody with hemophilia experience was in our network. It's stressful for us to have to start the infusion and not know who was going to be coming.

Participant 2 described similar circumstances.

***Lack of privacy from home care.*** Participant 2 described that although it is very helpful to have home care nurses for her step-son, that it can be difficult to always have nurses in their living room. She stated, "The nurse would be in our living room when we got home...the kids would spend a lot of time upstairs in their bedrooms to get away from that. But two years ago we had our lower level re-done and now that's Ryan's space."

**Child with Illness or Medical Condition.** Several themes emerged in the data concerning challenges and barriers for the children with a chronic or terminal medical condition or illness. The experiences are hardest for the child themselves, but each parent reported with great empathy that it is difficult for them to see their child experience these things.



***Physical pain.*** Many of the caregivers reported that the physical pain is one of the hardest factors for their children. Participants 3 and 4 described that their children had to endure many “pokes”. Participant 2 reported that her step-son’s pain cycles are very difficult.

***Fear of medical procedures and professionals.*** The parents reported that their children are often afraid of the medical professionals and the necessary procedures. Participant 4 stated, “Doctor appointments can be hard because he doesn’t like the veins in his arm accessed. He also resists getting his meds; he doesn’t want to get poked.” Participant 3 described his child’s fear of the white coats. He reported, “Number one, every time he would see a white coat he would scramble for me or my wife.”

Participant 1 reported:

He hates the hospital. He was MRSA positive and they always had to wear masks and gowns and they always made him feel uncomfortable. They scared him. The whole going to the hospital is hard...even now he’s scared and doesn’t want to go.

***Lack of communication skills.*** Most of the parents reported that it is hard that their children are not able to communicate their feelings well, either partially due to the illness, due to developmental setbacks because of the condition, or due to age. Participant 1 stated, “With his current trache, he can’t talk. So communication is a big problem for him. He makes a little bit of noise and pops his lips, but that’s also a big problem for him.” Participant 2 also reported that it’s also challenging that her step son isn’t able to tell them when something is terribly wrong other than by crying. Participant 5 also

reported that his son “still doesn’t talk” and said that it is one of the hardest things for him.

*Being different from other kids.* The parents expressed that their children’s medical conditions hold them back from experiencing life as many other children experience. Participant 4, who’s child has severe hemophilia, said, “The hardest thing for him would be that he can’t do things that other kids can do. He hasn’t experienced the extent of it yet.” Participant 1 also said that her son experiences problems in this area. She said:

With his current trache he can’t talk... He does this thing where he pops his lips to get your attention and some kids will copy and do that. When he talks his voice is scratchy and other kids will do that same thing towards him...and I know that he finds it hard that other kids won’t play with him sometimes because they can’t understand him. He’ll come home crying sometimes and I feel so bad.

Participant 3 described that his son struggled to understand why he was one of the few people that had illnesses. He stated:

I want to say it was about 3<sup>rd</sup> grade, he had to have a procedure and it was the only time I ever hear him say ‘Why me? Why is it always me?’ and that was hard for him trying to figure out and put some meaning to it.

Participant 2 spoke about the many ways that her step-son is confined from most activities and then stated, “I think it’s good sometimes that his cognitive skills are so low...because he doesn’t understand what a low quality of life he has and what he’s missing out on.”

***Unpredictability.*** Participant 1 reported that it was hard for her son to have an unpredictable schedule. She stated, “He never had a set schedule” when asked what has been hardest for the child.

***Siblings.*** Other themes emerged in the data concerning challenges and barriers for the siblings of children with a chronic or terminal medical condition or illness. Several themes can overlap between parents and siblings or child and siblings, but the following are the ones that stood out as affecting the siblings most specifically.

***Less attention and being treated differently than ill child.*** Most predominantly, parents reported the siblings as having difficulty dealing with having less attention than their brother who needs medical treatment. Participant 4 shared, “Attention that is given to Brandon is probably the hardest thing for him...he also doesn’t understand why he is punished differently....if he hits his brother, even lightly, it could cause a serious injury to Brandon.” It’s also hard for siblings to understand being treated differently than their ill brother or sister. Participant 1 also reported her older son struggling with the attention that is being taken away from him. Participant 1 stated:

I think it was just not having his mom around all the time. And having to spend the night at the hospital...having to be rushed to the emergency room and then we’re gone for 3 nights. All that stuff is the toughest because he went from having a mom all the time to hardly ever.

Participants 3 and 5 reported that this has been hard for their other children as well.

***Seeing sibling suffer.*** Some participants reported that their other children had a difficult time knowing that their sibling is suffering. Participant 3 said:

Our daughter was always worried about her brother...even as the kids have grown up she would avoid his wrestling matches so that she could avoid seeing him get hurt. It was hard for her to cope with the pain her brother was going through.

Participant 5 also reported that, "Seeing their brother suffer" has been the most challenging for his other children.

***Not knowing what will happen.*** Some parents reported that it was hard for the siblings to be in a place of "not knowing" very often. Many of the siblings don't understand what certain procedures mean, how serious or simple something is, when their parents or siblings will be around and when they'll have to leave, or even if their sibling is going to live or die, and that's hard. Participant 3 reported that his daughter never understood why they were always at the hospital. Participant 5 stated, "The not knowing is hard and scares them...is Isaac going to live or die today?"

***Embarrassment.*** Participant 2 spoke about what else has been challenging for her children. She reported:

I think there's also a little bit of embarrassment about it... especially my son, who was used to being an only child. This was a big change for him. They're all nice kids, so they haven't really said anything about it, but I can tell. It's hard when they don't have much space away from Ryan and the nurse, especially on days when Ryan's really loud...so they don't bring friends over much.

### **Positive Impacts and Helpful Coping Strategies for Families**

**Parents.** Themes emerged in the data as factors that are helpful for parents of children with chronic or terminal medical conditions or illnesses. Some of the themes are

opposites of the ‘negative impacts’ above, as expected, but these were spoken of in a positive light by the participants as to what has been helpful.

***Social Support.*** Social support from friends, relatives, and the community was discovered to be a large help to many families, but only if the people could understand and empathize with what the families were experiencing.

***Relatives and friends.*** Participant 4 stated, “My mom is a nurse, so she has been helpful. She moved closer to be near us, to help out.” Participant 3 experienced a lack of social support from relatives and explained that it would’ve been helpful if others could have helped out a little by getting on a schedule to bring a meal over once every two weeks or so, so that it didn’t take a huge bite of their time, but so that “it gives you something to look forward to.” He stated, “It’s a big hunk of the battle when everyday is a grind and we want to have something to look forward to.” Participants 2 and 4 also mentioned that it’s hard when you don’t have any care giver options. Participant 2 reported that although her husband’s previous divorce was horrible, that having every other week off from caring for Ryan is at the “top of the list.” Although Participant 2 reported that she doesn’t receive much support from her friends, she did say that her husband has long talks with his mother on the phone which seems to be helpful for him when he’s stressed.

Participant 5 reported that his church community is very helpful to his family. He stated, “Our church is our social outlet.” He also said that his faith community of people has been helpful with providing meals and babysitters. He stated, “I can’t deny them that they want to help. I need to allow them to be Christ to us. You can shovel my driveway, cook a meal...that was a job for a long time...finding things for people to do.”

*Professionals.* Participants reported that professional support, both emotionally and more concretely is helpful. Participant 1 reported that having medical professionals do every little thing to help her child feel normal was very helpful. She reported that the school district “bent over backwards to get a nurse for the school” that she picked.

Participant 3 also felt that professional support was helpful. He reported:

They had us meet with some other professional that told us that the biggest key that we had to keep in mind was to communicate. Communicate, communicate, communicate. He said that the tendency with human beings is to want to know why this happened or to blame someone for it happening and you can’t do that, or it will tear your marriage apart. Hearing that put into words what we kind’ve suspected anyway, but to hear someone like that say it who deals with situations like this a lot, helped to make it more real.

Participant 5 reported that the nurses at the hospital have been very helpful for them. He said that they’ve even volunteered and taken his child to watch over night.

*Families in similar circumstances.* Participant 4 expressed that meeting others who have a child with a similar condition helps. She said “The number one helpful thing is having the connection with other families. There are Facebook groups of moms and we’ve met people through the group.”

*Having some control.* Parents reported that they don’t have very much control when it comes to their child’s medical care, but being able to have some helps.

Participant 5 said:

It can be difficult for parents to give up control, so that when we do have control we hold onto it very strongly. I like to hold on to the little control and power that we have over our child and his life.

He also stated that his family has always been included in making decisions and that it's been wonderful. Participant 4 reported, "It's hard for me to give up any control over my son's medication to my husband because I'm a nurse.

***Finding meaning in the illness.*** Some participants described that it is helpful that they have found some meaning as to why their child has an illness or if they find a positive purpose behind it.

***Faith.*** Two participants reported that their faith is a big part of being able to cope and that attaching some meaning to a higher power is helpful for them. Participant 3 said that he knew that his family's situation was part of God's plan and participant 5 stated, "We have the mentality that this is our path" and "Our faith is extremely important." Participant 3 reported trying to give his son an answer as to why he is sick. He stated:

The only thing I could tell him (son) was 'Well apparently God has big plans for you and he's going to make you tough before you ever grow up', I don't know if that was right or wrong but it seemed to make sense for me and for him so that's what I said.

Another participant used his faith to find a meaning in the illness. He stated:

I am a big believer in redemptive suffering. That is the belief that in our pain we can unite with Christ on the cross and join him in the suffering and he joins us. That is probably the biggest thing that has been helpful to us. I can grasp a purpose behind the suffering.

***Point of view.*** Some participant reported that purposefully taking a different point of view of the situation helped significantly. Participant 3 reported that taking each day, one at a time, was helpful. He stated:

My wife and I pretty much decided that we'd take it one day at a time and that we'd try to make something happy happen every day...even if it was just me tickling the kids before bed. It's so important because you never know when bad news would be coming down the pipe. That's part of our family make up. There's good and bad things every day so let's try to focus on the good. It doesn't hurt to think that everything will work out.

Participant 5 also stated that he and his wife's point of view on the entire situation is important. He said:

At first we decided not to do the surgeries and we decided to bring him home to love him until he died. Then the doctor came in and said that he thought he could do the surgery and that it would be a good 40% chance of survival. We said let's do our baptism and away we go. We accepted it...and who he was ok...everything else we view as a gift. We really do feel as though it's been a gift these past 4 years.

***Distraction.*** Participant 3 also reported that doing fun things to get their minds off of the situation is helpful. He said, "We'd take them to Twins games, to the Minnesota Zoo, to Disney on Ice, to the movies, and anything that could make my kids laugh." Participant 2 reported that getting away and taking a drive is helpful for her. She also reported that exercise is helpful. She also reported that her husband is able to relieve stress by finding distractions. She stated:



He plays guitar, so sometimes if his son is having a really bad day and is screaming, he'll go down to his guitar room and just play for an hour. It's his way of disappearing for a while I think, and focusing on something different. And driving too, he does that sometimes.

***Housing near the hospital.*** One participant described his family's experience with having to seek treatment out of his home state. He was thankful that the Ronald McDonald house existed. Participant 3 reported:

Basically we moved into the Ronald McDonald house... my son needed chemotherapy at 7am and 5pm every day. I would leave at about 4am to get back to my job in Iowa on Monday morning, work late because it wasn't cool coming home to an empty house each night, and I'd leave again at noon on Friday. The Ronald McDonald house was a Godsend to us, because they only charged \$5 a night.

Participant 5 lives near the hospital and stated that "it's a blessing to be close by."

***Having a good relationship and trust with medical professionals.*** The participants reported that it's extremely helpful when they have a good relationship with the medical professionals such as social workers, doctors, nurses, and specialists. Having a good relationship was defined by the participants more specifically as having a good rapport and open communication, by the professionals understanding their situation, and by the professionals specifically addressing the children in meetings.

***Rapport and communication with hospital workers.*** Some participants reported feeling lucky to have a good rapport with the workers at hospitals and clinics. Participant 4 shared:

The positive experience has been that we have a great relationship with all of the people at the clinic. We hear that many don't and we feel lucky that we do. They do a good job of collaborating and we like that we are involved in his care. His nurse always follows up within a day if I call to see how he's doing. We can tell that they really do care for him.

Participant 1 expressed that having a good rapport has been helpful to her and her family.

She stated:

All the constant people...like the constant doctors and nurses...he was there so much that they knew him by name. They know him and they know us. It's always been easy to not have to explain everything that's wrong with him. It's nice to know that people are there and they care...the people that know him and you can tell they care.

Participant 1 also stated that it's extremely helpful that she is able to trust the hospital workers. She said:

He was there for a month and they would always come in his room and show that they cared. I had a nurse that would call and let me know every single thing that was going on with him. They even had volunteers that would come in and hold him and rock him. Having all those people there when I couldn't be was so nice...it was nice to know that he was being well taken care of.

Participant 3 reported that building a rapport between the hospital staff and the parents is very important and that it's important not to get too personal too fast.

Participant 2 stated, "Being patient, nice, and a good listener is important."

*Hospital workers understanding the situation.* Caregivers expressed that it's helpful when social workers and medical professionals understand their situation without the parents having to repeat it from the beginning to everyone. Participants 2 and 3 both mentioned that it's helpful when they can tell that the staff "get it." Participant 5 reported that it's important to him that the medical professionals have understood his family's beliefs and what their goals for their son are. He also stated, "Communication is really important. They should be able to read where parents are at."

*Hospital workers addressing my child specifically.* Participants reported that it's especially helpful and very appreciated when their child is addressed by the professionals. Participant 1 appreciates that the medical professionals see her son as a whole and "not just a kid with a problem." She also stated, "I want professionals to understand that my child is not just the kid in room 410 and that he is a person, not just a room number. That is so important."

Participant 3 also spoke about the importance of seeing the hospital workers speak directly to the child and the importance of the hospital professionals have a caring, sensitive attitude. He stated that "it's maddening to see your kids treated like an object...because the kid is important." Participant 5 stated, "It's important to be available and to know the kid's names."

*Education around the child's condition.* Some caregivers reported that the education that they received around their child's medical condition or illness was helpful to them. Participant 1 stated:

I think what was most helpful was that before they allowed us to take our son home with us, they has us take little mini classes on how to take care of his trache.

I think that was really helpful. Now I can take care of him. I can suction him and I can take his trache out to make sure he's okay. That was the most helpful for my son's father.

***Childcare during meetings.*** It was reported that it's hard to talk *about* their kids when their kids are in the room. It was reported that it's preferable to either have childcare or to directly include the child in the conversation. Participant 4 stated, "It's helpful for him to be involved in his care....and the child life specialist have been helpful by providing childcare so that we can meet alone." Participant 3 also reported that it is uncomfortable to talk about your child as if they weren't sitting right there. He said that it children might take that internally and may start to feel guilty for being ill.

***Recreational programs offered by the hospital.*** The programs and events sponsored by the hospital are helpful to families. Participant 4 stated, "Our clinic is very helpful, the hemophilia treatment center through our children's hospital...they sponsor events for families with bleeding disorders which is very nice and allows us to connect with other families."

***Financial resources.*** Many participants reported that one of the biggest helps has been the financial assistance that they have received. Participants 2, 3, and 5 reported that funding from hospital programs, counties, and charities for various things such as medical equipment, recreational activities, and even parking has been a very big stress reliever. Participant 2 stated, "Our biggest help have been the county social workers who helped us get the funding for the chair lift and the bath chair. Now they're paying for wipes because he's big and need big, adult wipes...a lot of financial resources." She also stated, "There's so much equipment out there that would be fine, but if you get it used the

insurance won't cover it. There are places where people buy and sell used medical equipment that's great."

***Home care.*** Two participants reported that having services at their homes has been very helpful to them. Participant 1 reported having nurses there to help her with her baby when he was first diagnosed. Participant 2 said:

Things are better now because of the services that we have in place. He has nurses that come to the home. They are there for 12 hours a day. We are able to work and actually do some things on the weekends because of them.

***Child with Illness or Medical Condition.*** Several themes emerged in the data as factors that are helpful for the children with a chronic or terminal medical condition or illness.

***Being involved in the medical care.*** Many parents reported that it's helpful when their children are involved in the care. Participant 4 stated:

It helps him to be involved. He pushes the factor 9 in and takes his needle out with help. He also likes to practice. He knows he has it [hemophilia]. It's important to keep the child involved in his care.

Participant 3 reported that having honest communication with his child was helpful for his son. He stated:

We tried very hard not to mislead him. We kept him involved and would explain that we'd *have* to go to the doctor...and he'd cry...and we would explain why. He learned to rely on us and trust us, even when it came to the white coats. We just reassured him.

Participant 3 said that eventually his son started thanking him for having open communication with him about his illness and would seek out his parents whenever he had questions.

***Medical play kits.*** Some caregivers reported that receiving medical supplies from the hospital social workers and child life specialists has been very helpful to their children. They are able to understand what the medical tools are used for so that their fear is lessened and so that they are more involved with their treatment. Participant 1 said, “I think we did meet with one [a social worker] once who gave us toy medical supplies to take home for our children to play with and to learn what to do, which was really cool.” Participant 5 also reported that the child life specialists have been very helpful for his son at the hospital. Participant 4 reported that her child used medical play supplies to learn about procedures for his condition and that it’s been very helpful.

***Knowing their not alone.*** Most parents also reported that it’s helpful for their children to know that they aren’t the only ones with an illness. Participant 4 stated, “The connection to social supports and other families are important; it helps the children to know that they aren’t alone.” Participants 3 and 5 also reported that it is helpful for their children to know that there are other kids out there with conditions like theirs.

***Rapport with medical professionals.*** Most participants reported that it’s been very helpful to their children if they are comfortable with the hospital professionals. Participant 1 reported that it is helpful to her son that the doctor tries to get her son excited and comfortable with who he is. Participant 5 agreed, saying “He oddly likes the hospital...he knows them and likes them for the most part. For me to leave him isn’t a big deal because they know him so well and he’s comfortable with them.”

***Distractions during procedures.*** Caregivers reported that distractions are helpful to their children during procedures at the hospital or clinics. Participant 1 expressed her approval of the slide show game that is shown to her son sometimes, so that he is distracted by looking for objects in the room. She stated, “Having something there to distract him right before he goes into surgery really helped...because usually he is kicking and screaming, so the distraction game is really helpful.” Participant 5 reported that it’s helpful that the nurses can “do a mitro-valve replacement [an unpleasant procedure] really fast.”

***Music.*** Two participants reported that music has been a helpful coping tool for their children. Participant 2 reported that music is very helpful and soothing to her step-son. And participant 5 reported that the music therapy his son receives has helped him and made him happy.

***Not being pushed too hard.*** Participant 2 also reported that not pushing him to be like other kids is helpful. She stated, “In the beginning I would push to have him get out, but over time I’ve realized what his dad sees ...that it’s the most important for him to just be happy and comfortable where he wants to be.”

***Siblings.*** A few themes emerged in the data as factors that are helpful for the siblings of children with a chronic or terminal medical condition or illness. They include alone time with a parent, communication about the illness, and involvement through the hospital.

***Alone time with parent.*** Parents reported that because attention is often taken from the siblings to focus on the other child’s medical treatment, that it’s helpful to have alone time with the siblings, but hard. Participant 4 said, “I’m not sure [what’s helped

him]...trying to make alone time has been helpful for him.” Participant 1 also found that creating special time for her other child to be helpful. She stated, “We found it easier for us to swap out days so I wasn’t gone all the time.” Participant 3 reported that during appointments “one of us would stay with Kevin and one of us would take our daughter and try to find something else fun to do... the playground at the hospital or the café.”

***Communication about illness and about death.*** Caregivers reported that siblings appreciate being able to communicate about their sibling’s illness. Participant 1 said that it was helpful that her son’s sibling could explain to others what was going on with his brother and that it helped him to be more comfortable around him. Participant 5 reported that faith is helpful for his other children and stated, “Talking about death with the kids helps. They handle it well. There’s sadness but we pray every night. It’s more real then.”

***Involvement with sibling through hospital.*** Participant 5 reported that the hospital programs have been helpful to his family and especially to Isaac’s siblings. He stated:

We get to go to stuff like Twins games and get free meals, music therapy, family life... child life comes out through the pain and palliative care program.

Phenomenal. Movies, games, and ice-cream social at the hospital...the Ronald

McDonald house does art projects...they love to come to the hospital.

## **Social Work Themes**

***Misunderstanding about Social Work Role.*** Misconceptions and confusion about social workers roles in hospitals and clinics were common among the data. Participants stated that it would be helpful if social workers could get the information about their roles out to the families in a more proactive way. Participant 1 stated:



I'm not really sure what the social workers even do. They could probably get the information out there more on what they can do. When we go to the hospital they always ask us a bunch of questions and they always ask us if we want to see a social worker, but I've always said no because I don't really know what they do.

Participant 2 also suggested that hospital social workers should offer more specific information about resources for families because she did not know that resources were available for many years. She said that open ended questions, such as "how can I help you," are not helpful. Participant 2 stated:

My advice to you then, if you are a hospital social worker, is to be very specific about what is available. Asking open ended questions about what you can do for us isn't really that helpful. Parents have no clue what is really out there. The help navigating the systems would be very helpful. We get questionnaires asking if all of our needs are being met and we think 'yea I guess,' but then we talk to someone else and find out that we can get help paying for things like a lift chair or a bath chair.

Participant 5 reported that social workers have asked his family if they need anything but that they always feel like they have it, because they aren't sure what else they could use. He later stated that it's important to communicate the things that are available especially if they've changed and to not assume what a family needs. He stated, "They use to offer us free parking all the time and we would turn it down...but now I think that we could use it and they don't offer it to us anymore."

**Social workers should push more.** Interestingly, parents expressed their feelings that social workers should encourage parents to take advantages of specific resources, even if the families deny it and it feels like they're being "pushed" to take the help.

Participant 4 stated, "We feel like she [the social worker] is talking to people who need it more. She comes in once a year to talk to us." Separately, participant 4 stated, "Sometimes I wish we had a little more contact with her, just checking to make sure that we are doing okay I guess...checking in a bit more...especially because she does understand and knows about it...maybe suggesting financial stuff." She also stated that it's important for families to have resources at home so that they feel empowered.

Participant 1 also agreed that it would be helpful for social workers to suggest for parents to take resources even if the parents didn't think they needed it yet. Participant 1 stated:

Even if families don't think that they need certain resources, it might be helpful for them to just get them anyway. It might've been nice to just sit down and talk to them about things and for them to go ahead and offer some things to us even though we thought we didn't need them. I always thought I could handle everything fine but people around me started to notice that I was losing weight because of the stress, so I think that it would be helpful is social workers went ahead and pushed a little more when offering things to parents.

Participant 2 also spoke about social workers pushing for families to take available resources. She stated:

Be very specific about the things you can do to help the family. Encourage them to accept the help. The pride gets in the way sometimes. Just help

with...overseeing the whole system...saying ‘this is what we have.’ Sometimes we don’t know what else we need...because we don’t know what’s available...like respite care...we didn’t even know that it was available until Ryan’s mom asked about it.

Participant 2 also offered some advice about how to approach families whose children have just been diagnosed. She stated, “Keep in mind how scary it is when a kid is diagnosed and help them through that process...make sure that they have the resources to deal with it.” Participant 3 had also reported that it is important to be mindful and sensitive.

**More can be done for marriages.** Participants 3 and 5 spoke with strong opinions about how more could be done to help couples struggling in their marriage due to their child’s illness. Participant 5 stated:

My cardiologist said that we handle our situation better than other couple. Why not do more for other parents as far as counseling and therapy? So many of them have gotten divorced. Why not address couples and their coping? That’s a big issue. It is very important and I think more can be done.

Both participants emphasized how much of a struggle having an ill child is on the marriage. Interestingly, both participants reported having a strong marital bond, but that they had witnessed other couples in the hospitals struggle with marital satisfaction throughout their child’s treatment.

## **Discussion**

The purpose of this research project was to discover what the effects are of having a child with a chronic or life-threatening illness on the family system by finding out what

has hindered or been challenging to the family during the time since the child has been diagnosed and by finding out what has been the most helpful to the family and each of its members throughout their experience. The purpose was also to find out how professionals, specifically social workers, can be of more service to these families. The following research questions were examined: What are the effects of having a child with a chronic illness? And how can social workers be more effective in treating families of children with chronic or severe illnesses? Following a review of the literature applicable to this project, my research findings indicate many similar and some contradictory results compared to the current research.

### **Effects of having a child with a Chronic or Severe Medical Condition**

Although 26 different negative aspects or central ideas were mentioned by the participants (17 for the parents, 5 for the child, and 4 for the siblings), and 27 different positive aspects, coping mechanisms, or central ideas were mentioned by the participants (17 for the parents, 7 for the child, and 3 for the siblings), only the most strongly held or commonly held thoughts or those mentioned in the previous literature will be focused on here in the discussion.

**Parents.** The most common negative impacts or challenges on the parents that were reported in this study were handling the initial diagnosis, seeing the child suffer, having fear of harming the child more, juggling work and treatment, lack of understanding and social support from relatives and friends, a negative impact on marriage, handling insurance and finances, and having to repeat their stories over and over.

Literature from Fisher (2001) and Hordvik & Straume (“Sick Children in the Family”, n.d.) did speak to the initial diagnoses being difficult for parents to handle, but fear about harming the child was not discussed. This is an important point. Participants reported that for very long periods of time that they were in constant fear of somehow harming their child and that this increased their stress levels and even created a barrier to bonding with their child. Perhaps more can be done within the hospitals or clinics to prevent these fearful and distressing feelings.

One of the most common themes found in the data was that it was extremely difficult seeing the child suffer. Parents were often time referring to the pain that comes with the medical conditions, but also having to see their child toted back and forth between medical facilities and being held down for pricks and pokes often. Perhaps being able to share these feelings and receive some support and validation would be helpful.

As previously mentioned, Badr & Kuster (2006), found that the variances of parental stress measurements usually started with two factors; the functional status of the child and the impact of the illness on the family. The family experiences more stress if the child’s functional status is low and experiences more stress if the impact of the illness is high (Badr & Kuster, 2006). Findings in this study indicated, the functional status of the children did not seem to play as much of a part as one study suggested, but perhaps only because a quantitative measure was not created for parents to compare to one another with. What seemed to make more of a difference was how much treatment the child needed to receive, which might be the equivalent of the impact of the illness in Badr & Kuster’s study.

The participants reported that lack of understanding and social support from friends and relatives creates a challenge. Some participants reported that they thought that their friends and relatives would be more helpful than they actually were. Many participants frequently said that others “don’t get it.” Furthermore, one participant reported that it was frustrating that so many people didn’t understand how medical treatments such as chemotherapy worked and that they would often think that his son was cured after a few treatments. It was hard for him, emotionally, to explain that it didn’t work like that.

As expected, caregivers reported that it is a challenge to manage their day jobs and their child’s treatment. Often times the parents have to take turns. Perhaps this plays into the negative impact that having an ill child has on marriage. Although little information was found on the impact that this can have on marriage in the literature review, 4 of the 5 participants mentioned this in the interview. Hovey (2005) found that mothers are often seen as the primary caregivers in the families by fathers. In this study, there were reports of females being considered the head of the household when it came to care and treatment of the child, and that this caused some resentment towards the husbands. It’s also important to mention other stressors on the marriage. Every participant reported that it was hard to find caregiver options for their child with the medical condition because it’s difficult to trust someone to take care of their child who is already vulnerable, and because others are often times afraid to care for their child. This alone can have a huge impact on a marriage. The financial stress, the busy schedules, the time it takes to deal with the insurance companies, and the constant worry are all things that could contribute to a stressful marriage.

As mentioned in the literature review, George et al., 2006 found that parents are triggered by factors such as hurtful comments from other people, being asked to repeat the child's condition, hearing stories about death, the deterioration of the child's health, and uncertainty when going for tests and medical appointments with their child. These participants did not report having to deal with many hurtful comments from others or that they have had trouble witnessing the deterioration of their child's health, perhaps because for some it has not deteriorated, but they did report that it's stressful "not knowing" what will happen. Being in a state of uncertainty can be very uncomfortable and stressful. A few caregivers also reported that it is very hard to hear about the deaths of other children at the hospitals while worrying about their child.

Many of the participants reported that it was hard to have to repeat their stories over and over. One participant felt so strongly about it that he wanted to be able to speak to hospital professionals publically. It was stressed that it is very important to know how many times a family or a child has visited the hospital because having to re-tell their story to each medical professional re-opens old wounds and forces them to re-live the moments. This has huge implications for hospital social workers.

Another similarity was found in the literature about the ways that different genders cope. According to Hovey (2005), men have more concerns about doing activities together as a family, about making sure that their family is happy and comfortable, about talking with and understanding their families, and about having enough fun and relaxation. This corresponds with the findings in this data; more men than women reported that going out and doing things together as a family such as baseballs games, movies, and trips to the zoo was more helpful for them than many other

things. And Lightsey & Sweeny (2008) found that women more frequently used emotion-oriented strategies to cope with chronic illness of a child and that women who used less emotion-methods experienced higher family satisfaction. There were more reports from or about the female caregivers using negative emotion-oriented strategies such as crying or feeling guilty than the men. However, it was also reported that the women tended to use more social supports. Findings in another study in the literature review found that fathers are the least likely of the family members to perceive social supports in their environments, (Ferrari, 1986). These findings somewhat correspond with this because the men (or reports from the women about their husbands) were more likely to report taking a drive, playing a musical instrument, learning about the medical conditions, or doing activities with their wife and kids, which are all either isolated strategies or strategies that only reach out as far as their immediate family. Interestingly, it was also noted that because the women are often the ones in charge of the medical care that it was easier to make connections with other women in similar circumstances, and that perhaps if men were given more opportunities to connect with other fathers that it would be helpful to them as well.

As discussed in the literature review, Brehaut, et al. (2009) said that “caregivers who feel *burdened* by caring for children with relatively *mild* conditions may fare more poorly than caregivers who feel *less burdened* by children with more *severe* health problems, (p. 1258). While the functional status of the child plays a role, the feelings and experiences of caregivers are contextual and can vary based on personal perspectives. This was hard to measure within the study. However, one of the participants stated that they viewed everyday that their child was alive as a gift while another participant stated



that they worried about their child's quality of life. This leads into a very important theme that was concluded from the data; point of view is very significant. Some of the participants pointed out that having an optimistic or "appreciate the good" point of view is very helpful for them.

This data corresponds well with the literature from McCubbin et al. (1983), who found that the coping patterns that parents appear to find value in the most were: (a) Maintaining family integration, cooperation, and an optimistic definition of the situation; (b) maintaining social support, self-esteem and psychological stability; and (c) understanding the medical situation through communication with other parents and consultation with the medical staff, (p. 328).

In this study, the positive coping strategies and helpful factors that were most commonly reported among caregivers included having social support from relatives, having support from professionals, receiving financial aid, hearing the medical professionals address the child specifically, having a rapport with the professionals, having a positive point of view, attributing a meaning to the illness, using distractions, talking to others who "understand", and having access to child care. Most of these factors were reported by the research in the literature review. For example, Lightsey & Sweeny (2008) and Sherman & Simonton (2001) found that persons who attach a meaning are more likely to tolerate the stress and are able to utilize more coping skills. Although the participants did not report on how well they perceived themselves to be coping, the participants in this study that attributed a meaning to the illness seemed to have stronger family cohesion, more reliance on one another within the immediate family, and expressed gratefulness for what they do have. The same participants reported that having

a positive point of view and holding on to the good things that they can is very important in coping too.

In another study, Brewer et al. (2007) found that the most helpful factors consisted of the following: others listening and believing in the family, others being flexible, the support being consistent over time, and doctors being honest with the family (Brewer, et al. 2007, p. 44). All of the participants stated how important it is for them to speak with others who “get it” because many of them reported that most people don’t. Support from relatives and friends was the most sought after, however, support from other families who have a child with a similar medical condition or illness was reported to be the most helpful to those who had connections to those families. It was also reported that having honest, clear communication, support, and rapport with the medical professionals is extremely important. One participant reported that his family would not have been able to cope at all if they had to work with a professional that was not emotionally supportive.

Child care was an unexpected common theme that arose within the data. The participants reported that it was difficult to not have breaks, and that child care was extremely helpful for them when it was available. Child care poses a problem for parents of children with medical conditions because it can be difficult to find someone who is willing and able to care for the child and because finances were reported to be problematic for most families. The participant with the highest income reported that the medical care and treatment for their child was extremely expensive, even with insurance. Parents don’t often have extra money to pay for child care. This could most likely be tied in with marriage satisfaction also.

**Child with the medical condition.** Children experiencing a chronic illness are bombarded by changes that are directed by others. During this, the process of normal childhood development is often disrupted (Frels, Leggett, & Larocca, 2009). However, the most commonly reported negative effect on the child with a chronic or life-threatening medical condition in this study was feeling different from most other children. Perhaps more can be done to address the shame and guilt that comes with having a medical condition. Other common negative effects included developing a fear of the medical professionals, experiencing pain, and having difficulties with communication, often due to the condition or due to disrupted development.

Findings from studies suggested that these children's abilities to cope with common stressors and illness-related stressors are "enhanced rather than impaired", compared to non-chronically ill children and adolescents, but no data was received in this study to support this, (Hampel et al., 2005 ). Instead, the most common helpful factors that were reported included being involved in the medical care and treatment, using play (such as medical equipment) to ease fears and learn about their conditions, and knowing that they are not alone by hearing about other children who are going through similar experiences.

**Siblings.** The most commonly reported negative effect on the siblings was reported as receiving less one-on-one attention from parents. This concurs with the literature that said that less time and attention from immediate family is available and less concern is shown from other family members which can cause feelings of jealousy and thoughts of being loved less to arise, (Sick Children and Families, n.d.) All of the participants reported noticing that their other children wanted more attention from them.

Seeing their siblings suffer was the second most common negative. In the review of the literature, Menke (1987) found that the majority of school-aged children who had siblings with chronic illness expressed worry about them, especially those with diagnoses that are potentially fatal, so this is not surprising.

However, according to Anderson & Davis (2011), siblings of chronically ill children have been found to have higher rates of psychosocial problems including psychological issues and behavioral issues. In this study, siblings were not reported to have any more behavioral or psychological problems than the ill child themselves. Another study shows that fathers are the least likely of the family members to perceive social supports in their environments, (Ferrari, 1986). However, mothers of children with chronic illness also perceive social supports to be lower than mothers with healthy children (Ferrari, 1986).

Naturally, the most commonly reported coping strategy for siblings was to spend some one-on-one quality time with them when able, even if it was just a simple walk over to a play room in the hospital. Some parents also found that switching off with the children was helpful, but this could start to cause a problem for the couple as well.

## **Conclusion**

Some of the negative effects that were reported by the participants in this study were also found in some of the previous literature. However, some of the previous literature discussed some negative effects that were not seen in these participants. Some of the most helpful coping strategies reported by the interviewees here did not appear in the previous literature. So the results here both contradict and support the previous research.

**Strengths**

Although the sample size was small, the children spoken about in this study represented a variety of medical conditions. Common themes among the parents' reporting still arose. This shows that despite the illness or condition that families in these circumstances share similar experiences within their families and within their experiences with medical professionals and social workers. The qualitative nature of this study allowed for the researcher to gather more in depth information from the participants. Although the semi-structured interview guide contained only 13 main questions, the researcher was able to diverge from the form to inquire further when it was warranted. Some of the strongest opinions and most valuable information was obtained by asking follow up questions or by asking the participants to expand on what they mean.

Because the participants all receive treatment for their children at hospital and clinics within the Metropolitan area in Minnesota, perhaps the data could be of some use to social workers at hospitals within the area. This information could be of great use to hospitals professionals who are looking to find ways to better serve or address the families that they care for.

**Limitations**

There are several limitations to this study. Qualitative research is exploratory in nature which limits the extent that the research can be generalized to the public at large. The participants in this study were recruited using the snowball sampling method, which is a non-random sampling technique, which limits the diversity of the subjects and collected data. All of the participants for this study lived in or near Minnesota, so this will also affect the diversity of the population. Most importantly, there were only 5

participants involved in this research study which drastically reduces the ability to generalize the information. Families who are dealing with a child with a medical condition have free time and energy to be used to volunteer for research. Perhaps the study would gain more participants if it were conducted over a longer period of time. The participants lived in a variety of residential settings, had a variety of employment statuses, income salary ranges, and different educational levels. There was also a 2 to 3 ratio of fathers to mothers or step-mothers, but 4 of the 5 participants identified as Caucasian and every participant had a child with a medical condition that was a male. Even though there were mixtures of some factors among the participants, the small sample size greatly affects the ability to generalize much of the information. These are all factors that contribute to the data being biased. As with qualitative research, it can be difficult to measure data against each other across participants. Perhaps more measurable information could have been gained with some quantitative questions directed at the participants' insight into their own coping, such as scaling questions. If the study were done again, it would be advised to ask questions such as, "How would you rate how well you are able to cope currently?, On a scale from 1 to 10?", so that participants' insights on their ability to cope can be captured. It would also be helpful if more detail could be gathered about how families cognitively cope, as in what types of things do they say to themselves to get by. Lastly, the researcher conducted all steps of data collection and analysis, and a researcher bias could exist that influenced the collected data and the analysis of that data. Future research, with a larger participant pool, will be needed to more completely address the effects and interventions for families with children with severe medical conditions.

**Implications for Social Work and Intervention Opportunities**

**Implications for practice.** The data gathered provides significant implications for professionals in the field of medical social work and perhaps even to other social workers who come into contact with families such as these. Some of the information could also be of use to other medical professionals who work in hospitals and clinics with children with chronic or life-threatening medical conditions and their families.

As was mentioned in the literature review, Anderson & Davis (2011) discovered that four types of practices were used the most when providing interventions for families with an ill child. These included disease specific educational training, stress point interventions, problem solving training, or therapeutic interventions, but not many of these practices developed actual coping skills within the family (Anderson & Davis, 2011). Perhaps sitting down with families to develop a model of actual coping skills could be useful to families. One participant said that it was very helpful to hear a social worker say, out loud, some of the things that they were already thinking; starting the conversation could be helpful. As many people have strengths and resilience, they probably already know of some strategies to use to cope when they are feeling overwhelmed, but perhaps having the discussion out loud with the family could be very beneficial, normalizing, and reassuring to them.

Several important messages were received from the participants in this small study. Perhaps they cannot be generalized due to the sample size, but several participants gave passionate feedback about their experiences and how social workers could be of more service.

***Role of social workers.*** Many of the participants expressed their confusion about the hospital social worker's role. Participant 1 shared, "When we he [son] goes into the hospital, they ask us a bunch of questions and they always ask us if we want to see a social worker but I've always said no because I don't really know what they do." This tells us a few pieces of information. (1) Other professionals are not encouraging or explaining to families why they might want to see a social worker and (2) social workers aren't being proactive enough and are only providing their services if they are requested. Perhaps this is something that could be changed in the hospital system so that families might be able to receive the full benefits that can be offered. A social worker can provide excellent services to a family going through crisis with an ill child. They can help patients and families understand a particular illness, they can help them work through the emotions of a diagnosis, provide counseling about the many decisions that need to be made, help resolve the social, financial, and psychological problems related to the health condition, prompt patient navigation services, advocate for patient needs, arrange for community resources, give referrals to other resources, offer grief counseling and bereavement care, and much more. Other professionals, such as nurses, should explain to families why they might want to see a social worker when asking the families. Or perhaps there should be a system that allows a social worker to stop by and talk with each family at least once a month, whether they have are only in the hospital once every few months or several days a week. Social workers and practitioners can offer their knowledge and support to meet the psychological, emotional, and sometimes physical or financial needs of the families. It should be clearer to families what the role of a social worker is and how they can be of service, right from the beginning of treatment.



***Offer specific resources.*** The feedback from this study tells us that hospital social workers should be more specific about the services that they can offer to families.

Participant 4 stated, “Sometimes we don’t know what else we need...because we don’t know what’s available.” Participants stated that it would be more helpful to them if the social workers could build a rapport with them and then offer specific resources or services. Another participant stated that it’s important to remember to continue to offer the supports even if the family has turned them down in the past.

***It’s okay to push resources and help.*** Surprisingly, almost every participant said that the social workers should “push” the resources a little more. Participant 4 said, “Encourage them to accept the help,” and participant 1 said, “I think that it would be helpful if social workers went ahead and pushed a little more when offering things to parents.” Participant 3 also reminded social workers, “Don’t walk in there like your there to scatter flowers around the room, because it’s not a fun time.” The overall message here was that sometimes parents feel as though they should accept the help because they should feel as though they can handle everything on their own. Later on, the parents may be more accepting to receive the help, but that’s often after they’ve really struggled. Social workers should encourage the families to stay in contact and to perhaps think more about the resources offered.

***More can be done for marriages.*** Another implication for social work that came up in the study was that more can be done to help married couples who have a chronically ill child. The stress of caring for a chronically ill or terminally ill child can quickly bring any marital issues to the forefront. One study found that parents of children with genetically based diseases, such as hemophilia, have a higher than 70 percent

divorce rate. Between all the stress and the appointments, there isn't much time for each other. However, there is conflicting evidence on the matter; Syse, Loge, and Lyngstad (2010) found that overall, divorce rates between couples with or without children with cancer were similar, based on a large sample size. Some participants within this sample felt that more could be done to help with the negative impact that having an ill child has on marriages, based on their personal experiences at hospitals with other couples.

Participant 5 asked, "Why not do more for parents as far as counseling and therapy? So many of them have gotten divorced....Why not do more to address couple and their coping? That's a big issue." The literature stated that Emotionally Focused Therapy (EFT) has been found to produce significantly higher scores in marital adjustment on the Dyadic Adjustment Scale (DAS), which is a self-reported measure of relationship adjustment, (Walker, Johnson, Manion, and Cloutier, 1996) when done with parents of children who have severe medical conditions. Perhaps more can be done within the hospital or clinic address this important issue. Whether parental divorces are more common among families with ill children or not, it is highly supported that illnesses can strain marriages. Classes and private sessions using EFT or Solution Focused Therapy (SFT) could be offered to parents more easily, perhaps through referral. Or perhaps more discussions could be done on this topic with families within the hospitals. The communication styles and coping skills of the parents *before* having a child with a serious illness is a large factor in the divorce rates, as one study has indicated, (Lankey et al., 1978). It may not be the illness that is what is driving the divorces, but the communication and coping styles of the parents, however, as one can see, having a child with a serious illness requires positive coping strategies and good communication skills

to be able to handle the situation. Perhaps more can be done to assess for families who may need the extra marital support after their child has been diagnosed. Hospital social workers could then refer families to the proper counseling services.

***Know the family's situation.*** Another message that was relayed was that it's very important for social workers and other hospital or clinic professionals to know why a family is there. Some participants reported that it's hurtful and hard for them to have to explain why they are at the hospital to each new professional. Participant 5 stated that his biggest piece of his advice was to know why the family is there and to know if it's their first time or one of many recurring visits. It can be painful, upsetting, and grueling for a family to have to re-tell their story each time they go to the hospital. It is important for social workers to have access to that information so that they may use it to interact with the parents appropriately.

***Take caregiver opinions seriously.*** A number of participants reported that their opinions are brushed over by professionals sometimes. A hospital social worker's job is to be of service to the patients, but also to help internally within the work culture as well. Perhaps if social workers educated other professionals about this, families could benefit.

***Recreational activities through the hospital are important.*** The recreational activities offered through the hospitals are a large support to the families with ill children. This provides an opportunity for families to interact with other families and for some joy to be brought to their lives during a difficult time. Participant 3 stated, "It gives you something to look forward to, which is a big hunk of the battle when every day is a grind." Participant 5 stated that the ice-cream socials, the baseballs game tickets, the art projects at the Ronald McDonald house, the date money from the pain and palliative

program, and other events and services have helped his entire family to cope because it makes them feel comfortable and cared for. The activities, often headed by social workers, are very helpful to families.

***Encourage support systems and self-care.*** This study found that the largest strategy for not only “coping” but for living a happy life with one’s family, no matter the circumstances of the ill child, is to communicate with others. It was found to be especially helpful for the parents and children alike if they knew someone else who has the same medical condition. It’s a way of supporting each other without fear of misunderstanding or judgment. Social workers are able to help establish connection bridges for families within the hospital through groups that meet or groups using social media so that parents can have those connections.

***Distraction is a helpful tool.*** This study found that distractions are quite helpful for the children with serious medical conditions and illnesses, while in the hospital or clinic. The use of games, visuals, and auditory distractions can help the children to cope with painful procedures or scary environments. Social workers should actively prepare other professionals and families to use distractions to help children remain calm and to be able to handle the experiences that come with treating severe medical conditions and illnesses.

***Implications for policy.*** This study has some implications for mezzo and macro level policies within hospitals. First, because so many of the participants reported not wanting to work with social workers because of confusion about the social worker’s role, it would be more useful if the social worker’s role could be explained to parents and families before they turn down the help. If nurses were educated more about the social

worker's roles, perhaps they would be able to explain it to the families better before asking if the families would like to visit with one. Or perhaps an informational sheet could be handed out before the family is asked. Hospitals could create a policy or guideline for nurses requiring them to learn what the social workers role are so that they can explain it to families when offering for a visit with one. And the best solution would be if social workers were required to visit with each family at each non-routine hospital visit by a family with an ill chronically or terminally ill child. This would of course, require more social workers on staff, so that each family would be given ample opportunity to speak and meet with a social worker. Secondly, because social workers are more attuned to a family's emotional and psychological needs than other medical staff, such as doctors and nurses, it would be helpful if social workers were able to provide some education to hospital staff about what the patients have reported as helpful and unhelpful when interacting with the medical professionals. Hospital social workers would then be able to pass along vital information to medical professionals so that a hospital's quality of service to families and their children can be improved. Social workers are a valuable asset both externally and internally within a medical facility.

**Implications for research.** Several implications for future social work research were drawn from this study. First, a larger sample size should be used in future research. And perhaps the participants could be divided up by chronic illness and life-threatening or terminal illness. It would also be helpful to have children who have medical conditions combined with low IQ or MR in a separate group. Secondly, it would be interesting to see the results from a combined qualitative and quantitative study. Family members' insights into how well they believe that they have coped on a scale, and over time, would have

been helpful in this study so that families members coping success and strategies could be compared to one another. Also, one of the most intriguing themes from the study is that more can be done to prevent divorce among married parents of ill children. There was a significant lack of research done in the area of marital counseling and coping with these families. Future research in this area could prove to be very helpful to families. Little research was also found concerning the sense of loss that accompanies a chronic or life-threatening illness. Some interesting research could be done regarding parents' and childrens' journey through the grieving of a "normal" childhood and anything else that may be lost due to the illness. Lastly, further research could be done to discover how resiliency and coping strategies can most efficiently be taught, built, and encouraged within families with an ill child, so that families can receive the full potential of support from their hospitals and social workers.

**Conclusion.** There are several ways that social workers can be more effective with families who have a chronically ill child that participated in this study. Some of the most significant ways to do this that were found in this study include creating more support and counseling for married parents, involving the children and parents with direct involvement in the medical treatment, offering more specific financial resources, educating medical professionals to express more understanding and empathy, and providing connections to other families and children experiencing similar circumstances. Medical professionals and hospital social workers could benefit from hearing more personal in depth stories such as these so as to provide higher quality services to families experiencing this type of stress. These dedicated parents and vulnerable children deserve to have all the care and support that hospitals and social workers can provide.

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## **Appendix B**

### **Telephone Script**

Hello! Thank you for calling me. As you know, my name is Morgan Wilson and I am a MSW student at St. Catherine University and the University of St. Thomas. For our final year of graduate school in the clinical social work program, we are required to complete an applied research project, complete with a research paper and public presentation in May. My topic focuses on the experiences of families with a chronically or terminally ill child and how professionals can be more helpful. I have an information sheet about the study that you may or may not have read yet. If not, I will send it to you or can read it to you now.

As my information sheet stated, participation includes participating in a live interview that will be audio recorded in a private room with a closed door of your choosing or at a library room reserved in advance. This may be at a public library or a library at the University of St. Thomas or St. Catherine University. At the start of the interview you will be asked to read and sign a consent form. Participation in this research project is voluntary and a participant can decide not to participate at any time throughout the research process. Due to the sensitive nature of the questions, I will periodically ask if you are comfortable to proceed or if you would like a short break. The information collected during my research will remain completely confidential. Data will be kept on my personal audio recording device at my home in a locked room when not in use. After completion of this research project, any identifying information and electronic data will be permanently deleted and any physical data, such as transcriptions, will be destroyed. Do you have any questions about the process? Based on my information sheet, I was wondering if you would agree to participate in my research?

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**Appendix C:****INFORMATION SHEET FOR THE STUDY**

My name is Morgan Wilson and I am a graduate student in the MSW program under the direction of Catherine L. Marrs Fuchsel, PhD, LICSW in the School of Social Work at St. Catherine University and the University of St. Thomas.

I am conducting a research study to explore the experiences of families that include a child with a chronic or terminal medical condition or illness. I am interested in learning what concepts and supports help and work best for the family and what things have been unhelpful. I am also interested in learning how professionals, such as clinical or hospital social workers, can improve their services to adequately meet the needs of families with chronically or terminally ill children.

I hope that what I learn from this study will help social workers and other professionals to understand the impact of having a child with a chronic or terminal illness and how it affects each member of the family and the family dynamics. I am inviting mothers, fathers, and other caregivers, who currently have a child with an illness or have had experience with a child with an illness in the past, to participate in this, single, interview. I would like to interview the parents or caregivers about their experiences and about their children's experiences in one interview that will be about an hour long.

I understand that this may be a sensitive topic and every pre-caution for the participant's comfort and psychological safety will be taken. The interview will be conducted in a private room of the participant's choosing. This interview could also be conducted at a room with a closed door at a public library or at the library of St. Catherine University or the University of St. Thomas. The participant and the researcher will work together to find a time that is convenient for both parties. This study is voluntary and the participant may stop the interview at any time. The participant may also choose not to answer any question. The participant may take a break from the interview at any time upon request.

In the interview I will ask you several questions about your family's experience with having a child with a chronic or terminal illness or medical condition. Some will pertain to yourself and other adults in the family, some to the child and their siblings, and some to the professionals involved with your child. However, only parents or caregivers will be interviewed. The participant may receive a list of the question prior to the interview upon request.

The only direct benefit to you for participating in this research project is the \$10 coffee gift card you will receive. It is possible that this study will help other social



workers in practice by exploring the impact of families experiencing having a child with a chronic or terminal medical condition or illness. The information from this study will be published online through St. Catherine University. Your name or other identifying information will not be used and the information will be recorded anonymously. Any identifying information that I know about you will be kept completely confidential.

The interviews will be audio-recorded and they will not be recorded without your permission. You will have the right to ask for the recording to be stopped. The audiotapes will be kept on the researcher's private audio recording device will be kept in the researcher's home office, which is kept locked when not in use. Only the researcher will have access to the confidential information. The research assistant will have access to the transcriptions of the interviews, but no identifying information will be included and the research assistant will still be bound by confidentiality. The data will be destroyed after the public presentation of the research findings in May, 2014. The audio recordings will be digitally deleted immediately after they have been transcribed.

I sincerely appreciate your interest in my research study. Please follow up with me to move forward.

**Contact information:**

**Morgan B. Wilson**

**Cell phone: xxx-xxx-xxxx**

**E-mail: Xxxx@stthomas.edu**

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact Catherine Marrs Fuschel at xxx-xxx-xxxx.

## **Appendix D**

### **Families with Chronically Ill Children RESEARCH INFORMATION AND CONSENT FORM**

#### **Introduction:**

You are invited to participate in a research study investigating the experiences of families with children who have chronic or terminal medical conditions or illnesses. Morgan B. Wilson, a student in the MSW Program at St. Catherine University and the University of St. Thomas, is conducting this study under the supervision of Catherine L. Marrs Fuchsel, PhD, LICSW in the School of Social Work. You were selected as a possible participant in this research because of your experience of caring for a child with a chronic and/or severe condition, as it relates to the research topic. Please read this form and ask questions before you decide whether to participate in the study.

#### **Background Information:**

The purpose of this study is to investigate what has been helpful and what has been unhelpful to these families throughout their experience and to find out how professionals, particularly social workers, can service them better. Approximately eight people are expected to participate in this research.

#### **Procedures:**

If you decide to participate, you will be asked to partake in an individual interview with the researcher either in a private office or location of your choosing, in a rented room at the University of St. Thomas library or the St. Catherine University library, or at a public library. The interview will last about one hour for one session and will be audio recorded for data analysis purposes. We will have a short debriefing after the interview is over.

#### **Risks and Benefits:**

The study has minimal risk. It is a sensitive topic and may be difficult for some to talk about, but pre-cautions will be taken by the researcher to assure comfort and safety. The participant may stop the interview at any time. Counseling resources will be provided to each participant after the interview. Some of the resources involve a cost, which is indicated on the list. The Interprofessional Counseling Center and the Crisis Hotline are free of charge.

The only direct benefit to you is the \$10 coffee gift card that you will receive for participating in this research. However, the research may benefit families with chronically or terminally ill children in the future.

**Confidentiality:**

Any information obtained in connection with this research study that could identify you will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented. I will keep the research results in a password protected computer in the researcher's home. Only my research advisor, my research assistant, and I will have access to the records while we work on this project. However, the research assistant and my research advisor will only have access to data with no identifying information included. I will finish analyzing the data by May 23rd, 2013. I will then destroy all original reports and identifying information that can be linked back to you. The audio recordings will only be accessible to the researcher and researcher assistant and will be erased upon completion of the research project by May 23rd, 2012.

**Voluntary nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University or the University of St. Thomas in any way. Participants can refuse to answer any question asked during the interview. If you decide to participate, you are free to stop at any time without affecting these relationships, and no further data will be collected.

**New Information:**

If during course of this research study I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings.

**Contacts and questions:**

If you have any questions, please feel free to contact me, Morgan B. Wilson at xxx-xxx-xxxx or by email at Wils7806@stthomas.edu. You may ask questions now, or if you have any additional questions later, feel free to contact me later. The student faculty advisor, Catherine L. Marrs Fuchsel is also available for questions, at xxx-xxx-xxxx. The St. Kate's Institutional Review Board contact is John Schmitt, PhD, IRB Chair: xxx-xxx-xxxx. You may keep a copy of this form for your records.

**Statement of Consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after

signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

I consent to participate in the study and I agree to be audio recorded.

---

\_\_\_\_\_  
Signature of Participant

Date

---

\_\_\_\_\_  
Signature of Researcher

Date

**APPENDIX E****Transcriber/Research Assistant Confidentiality Agreement****Researching Experiences of Families with Chronically Ill Children**

I am conducting a study to address the experiences of families with chronically or terminally ill children. This study is being conducted by: Morgan B. Wilson under the advisement of my chair, Catherine L. Marrs Fuchsel, Ph.D., LICSW, St. Catherine's University and University of St. Thomas.

**Confidentiality:**

Confidential information includes all data, materials, products, technology, audiotapes, computer programs and electronic versions of files saved to portable storage devices. One-time audio recorded interviews lasting no longer than 1 hour will be conducted by the researcher. The completed audio recordings will be hand delivered to you by the researcher for transcription or coding. No personally identifying information will be attached to the audio recordings. Any transcriptions or electronic files produced by you will not include information that will make it possible to personally identify participants in any way. All audio recordings and transcriptions are to be kept in a locked file. No one else will have access to the records. No one else will have access to the computer on which transcriptions and electronic files will be prepared. All audio recordings, transcripts and electronically formatted transcripts will be returned in their entirety to the researcher. Once transcriptions or coding have been completed and an electronic file compiled, you will contact the researcher who will then personally pick them up. Any and all electronic versions of transcripts will be deleted from your files upon delivery of records to the researcher.

**Contacts and Questions**

My name is Morgan B. Wilson. If you have questions, you may contact me at xxx-xxx-xxxx or my research chair, Catherine L. Marrs Fuchsel, Ph.D., LICSW, at xxx-xxx-xxxx. You may also contact the St. Catherine's University Institutional Review Board at xxx-xxx-xxxx with any questions or concerns.

**You will be given a copy of this form to keep for your records.**

**Statement of Agreement of Confidentiality:**

I, \_\_\_\_\_, have read the above information and agree to confidentiality as stipulated above. I further agree not to disclose, publish or otherwise reveal any of the data obtained through the research.

**Appendix F**  
**Resource Handout**  
**Counseling Resources**

If you would like to talk to anyone about your experience, here are several counseling resources you can follow up with:

Center for Grief, Loss & Transition (651) 641-0177  
Specializes in transitions of family structures  
1129 Grand Avenue  
Saint Paul, MN 55105

MPSI Psychotherapy Center (612) 824-3800  
Psychoanalytic psychotherapy offered without the constraints of insurance requirements  
3108 Hennepin Ave. S.  
Minneapolis, MN 55408

Interprofessional Counseling Center/ Assessment Services (651) 962-4820  
Therapy provided by graduate psychology and social work students free of charge  
1128 Harmon Place, Suite 100  
Minneapolis, MN 55403

Bridges and Pathways Counseling of Woodbury (651) 829-6610  
Therapy for individuals, couples, and families.  
563 Bielenberg Drive #145  
Woodbury, MN 55125

Valley Counseling & Clinical Psychology (715) 953-2045  
1810 Crest View Dr., Suite 2D  
Hudson, Wisconsin 54016

Crisis Connection is a non-profit mental health counseling agency providing telephone counseling services, specializing in crisis counseling, intervention and referral.

- Available to all callers throughout Minnesota, free of charge
- Immediately accessible
- 24 hours a day
- 365 days per year
- Confidential
- Able to respond to any problem
- Delivered by skilled counselors

**The Crisis Hot Line (612- 379-6363)**

**APPENDIX G****SEMI-STRUCTURED INTERVIEW GUIDE**

Demographic Information:

**1) Gender**

What is your gender?

Male

Female

**2) Marital Status**

What is your marital status?

Married

Widowed

Divorced

Separated

Never married

**3) Racial/Ethnic**

What Racial/Ethnic identity would you describe yourself as?

American Indian / Native American

Asian

Black / African American

Hispanic / Latino

White / Caucasian

Pacific Islander

Other

**4) Children**

How many children do you have in your house under the age of 18?

2

3

4 or more

**5) Education**

What is the highest degree or level of school you have completed?

No schooling completed

Nursery school to 8th grade

9th, 10th or 11th grade

12th grade, no diploma

High school graduate - high school diploma or the equivalent (for example: GED)

Some college credit, but no degree

Associate degree (for example: AA, AS)

Bachelor's degree (for example: BA, AB, BS)

Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)

Professional degree (for example: MD, DDS, DVM, LLB, JD)

Doctorate degree (for example: PhD, EdD)

Would rather not say

**6) Employment Status**

Are you currently...?

Employed for wages

Self-employed

Out of work and looking for work

Out of work but not currently looking for work

A homemaker

A student



Retired

Unable to work

**7) Income**

What is your household income?

Under \$25,000

\$25,000 - \$49,999

\$50,000 - \$74,999

\$75,000 - \$99,999

\$100,000 - \$124,999

\$125,000 +

Would rather not say

**8) Living Area**

Which of the following best describes the area that you live in?

Urban

Suburban

Rural

**9) Can you tell me who is included in your family? Who do you consider your 'immediate family'?**

(You and your child? You, a boyfriend/girlfriend, and child? You, a parent, and child? You, a spouse, and your child? Etc.)

**10) How did your family function prior to the diagnosis or medical condition illness?**

Tell me a bit about your family and how things were before the diagnosis (or perhaps before the child was born, if the child was born with the condition) What was the "norm" like for you and your family prior? (ex. Relationships, roles, family unity, etc.)

**11) How did you or the family become aware of the child's medical condition or illness? What were the initial reactions?**

**12) What is or was the child's medical condition? Can you tell me a little bit about it?**

Use as much or little detail as your would like.

- 13)** How has the family dynamic changed in the time since the diagnoses?  
(Relationships, roles, family unity, thoughts and feelings, etc.) What has changed since the diagnosis of your child (or birth, if he/she was born with the condition) and what has stayed the same?
- 14)** (Key Question) What challenges have you faced during this time? What has been hard for you as the mother/father/caregiver?
- 15)** (Key Question) If applicable, what challenges has your spouse (or other adult family members, if any) faced during this time? What has been hard for him/her?
- 16)** (Key Question) What has been challenging to the child throughout this time? In regards to the medical condition? What do you think is hardest for him or her?
- 17)** (Key Question) If applicable, what has been most challenging to the siblings? What else?
- 18)** (Key Question) What has been the most helpful to you during this time? Throughout this experience? As the mother/father/caregiver? How have you been able to cope? Please tell about anything that has been helpful to you.
- 19)** (Key Question) What has been most helpful for your spouse? (Or other adult family members)
- 20)** (Key Question) What has been most helpful to the child during this time? How have they coped with this medical condition or illness?
- 21)** (Key Question) What has been the most helpful to the child's siblings during this time?
- 22)** What professionals have been involved with you and your child regarding his/her medical condition or illness? And have you ever worked with a social worker in regards to your child's condition?
- 23)** Can you tell me about any negative or positive experiences you've had with any of these professionals? Any that stand out to you?
- 24)** (Key Question) How can social workers (hospital social workers) be more effective in assisting families of children with chronic illnesses? How can they be of more service? What would you like for them to be able to do?
- 25)** (Key Question) What do you think is the most important for professionals to understand about you, your child, and/or your situation when working with you?

**26)** (Key Question) What do you think would be most important for a hospital social worker to understand?

**27)** What else would you like to add regarding this conversation? Is there anything that I've missed that you think is important?